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# A multidimensional scale to measure the reproductive concerns of young adult female cancer survivors

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## Abstract

**Purpose** Concerns about fertility and parenthood are important to many young adult (YA) female cancer survivors and are associated with poorer quality of life. We aimed to develop a new scale to comprehensively measure these concerns so that they can be better addressed.

**Methods** Scale development involved: (1) seven focus groups to identify reproductive concerns among YA female cancer survivors and develop potential scale items followed by pilot testing and cognitive interviews to refine items, (2) administering surveys to 204 YA female survivors and conducting principal components analysis (PCA) with oblique rotation to identify underlying factors in the multidimensional scale, and (3) identification of preliminary construct validity evidence.

**Results** We subjected 37 potential scale items to PCA, which indicated a six-factor solution. After removing low-loading and cross-loading items, we selected the three top loading items representing each factor. The 18-item Reproductive Concerns After Cancer scale ( $\alpha=0.82$ ) assesses concerns about fertility potential, partner disclosure, child's health, personal health, acceptance, and becoming pregnant. As hypothesized, women who wanted to have a baby ( $p<0.001$ )

and those for whom having a biological child was very important ( $p<0.05$ ) had higher mean scores, indicating higher concerns.

**Conclusions** The scale demonstrated good internal consistency and evidence of construct validity and holds promise for future clinical and research applications.

**Implications for Cancer Survivors** An effective tool to identify concerns related to fertility and parenthood is essential for meeting the long-term reproductive health needs of young women who have survived cancer.

**Keywords** Cancer survivorship · Scale development · Oncology · Reproductive concerns · Fertility · Measurement

## Introduction

Cancer treatments can threaten future fertility and limit the parenthood options of young women who have survived cancer. Most young cancer patients will be exposed to gonadotoxic treatments such as chemotherapy and radiation that result in higher risks of infertility, premature ovarian failure, and fewer parenthood options in survivorship [1–5]. Prolonged endocrine therapy, while not directly gonadotoxic, requires a delay in pregnancy during which ovarian aging occurs and can further limit a woman's reproductive capacity [1–5]. Fertility preservation prior to cancer treatment is an option for some women and can increase potential biological parenthood options. However, even with clinical efforts to offer fertility preservation [5, 6], fewer than 5 % of young women undergo preservation procedures before treatment [7]. Consequently, many young women who have completed cancer treatment will have questions and concerns about their fertility [8–11].

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Despite professional society guidelines recommending a discussion of fertility risks with cancer patients, YA female survivors have significant unmet medical and informational needs regarding their fertility and parenthood options [8–11], which are associated with poorer quality of life in survivorship [7, 12–18]. Furthermore, their concerns extend beyond biological fertility potential to include concerns about recurrence, living long enough to raise children, and the health of their (potential) children [8–11, 19–22]. Biological parenthood is less likely among cancer survivors than in the general population [23–27]; the 10-year post-diagnosis pregnancy rate for females diagnosed between 15 and 44 years has been observed to be half of that expected [26]. This may be indicative of lower fertility rates as well as psychological, social/cultural, medical, and economic barriers to parenthood occurring later in the course of survivorship [14, 20, 25, 28]. Future parenthood options are important to many young survivors, but most of them are not adequately informed [10, 11, 29–32]. This research supports the need to generate a scale to identify the unique reproductive concerns of YA female cancer survivors so that they can be better identified and addressed.

Identifying reproductive concerns requires an assessment tool that can capture both breadth and depth. There is one existing scale designed to measure the reproductive concerns of adult female cancer survivors, the Reproductive Concerns Scale (RCS). The RCS is a unidimensional scale that yields a summary score of responses to 14 questions (e.g., loss of control over reproductive future, sadness about inability to have children) [16]. The scale has shown good reliability for the total score with English-speaking and primarily white (non-Hispanic) reproductive cancer and lymphoma survivors averaging 44 years of age ( $\alpha=0.91$ ) [16]. However, a factor analysis has not been conducted, and validity has not been established to date. Furthermore, the unidimensional scale does not incorporate the range of reproductive and parenthood concerns that young survivors have identified as important to them, such as those related to their personal health, their children's health, pregnancy, or disclosure issues [8].

We describe the process of developing a new multidimensional scale, the Reproductive Concerns After Cancer (RCAC) scale, to assess the diverse range of fertility and parenthood concerns of YA female cancer survivors (age, 18–35 years). We incorporated feedback from a diverse group of YA female survivors in order to develop a reliable, valid, and culturally relevant scale to measure those concerns. Based on our preliminary qualitative work, we conceptualized reproductive concerns as covering a multidimensional set of concerns related to fertility and parenthood in cancer survivorship [8]. Unlike the RCS, the RCAC scale will allow researchers and clinicians to identify a broad span of reproductive concerns important to YA female cancer survivors [8, 32, 33] to better recognize and address them.

## Methods

Phase 1: qualitative phase for item development and pilot testing

We conducted seven focus groups ( $N=22$ ) with YA female cancer survivors to explore their fertility-related and parenthood experiences and concerns. We used both clinic- and community-based methods to recruit participants (age, 18–34 years). Age at diagnosis ranged from 6 months to 30 years. Participants had 11 different cancer types, with the most common being lymphoma, breast, and thyroid cancer. Just under half were from non-white racial/ethnic backgrounds, with about a third reporting Hispanic or Latina ethnicity [8]. After an open-ended discussion of topics, which included access to reproductive information and care in survivorship as well as feelings toward fertility, pregnancy, and parenthood in survivorship, participants were asked to develop and revise potential items to assess their reproductive concerns after cancer. This process resulted in the development of 46 potential scale items.

Following completion of the focus groups, we invited nine participants to each complete a face-to-face individual cognitive interview to pilot test the web-based survey and further refine potential items. The interviews were about 1 h in duration. We asked participants to critically appraise key questions and response categories, including potential scale items, using a verbal probing technique (comprehension, paraphrasing, recall and probes about the way in which they arrived at answers and problems encountered) [34]. We also discussed the overall design and structure of the survey content, cultural sensitivity, and relevance to other young women diagnosed with cancer. We conducted cognitive interviews over two iterations and recorded them to ensure accuracy. In conjunction with general recommendations for scale development [35–37], these results informed item construction, including wording and response options.

Phase 2: administer items and conduct exploratory factor analysis

### *Participants and procedures*

We enrolled 204 YA female cancer survivors to complete one anonymous 20-min web-based survey. We recruited participants between the ages of 18 and 35 years via the Internet, primarily through social media outlets and local community outreach efforts. We directed cancer survivors who were interested in hearing more about the study to a website where they could review informed consent procedures and contact research staff with additional questions. Interested survivors completed a web-based screening form and, if eligible, were provided electronic informed consent and asked if they would like to participate. Those agreeing were directly linked to the web-based

survey. Participants completed a single online survey including questions about cancer and reproductive history, reproductive concerns, parenthood desires, and psychosocial outcomes. Because the survey was anonymous, we asked participants to contact us via the telephone to verify their survey completion before sending them a \$20 gift card incentive.

### Measures

We obtained information about demographic and cancer characteristics, including diagnoses and type of treatment received. We also assessed reproductive history, including attempted pregnancy, births, miscarriage, and infertility. Sources of study measures include the National Survey for Family Growth [38], Time to Pregnancy [39], and the Penn Ovarian Aging Study Menstrual Questionnaire [40], which gathers menstrual pattern data over the past year. We also developed new survey items to measure access to fertility information and care as well as feelings toward genetic counseling, genetic testing, and adoption. We finalized wording (e.g., inclusion of positively worded items) of all 46 potential RCAC scale items and wording of other new survey questions described above (e.g., measuring access to fertility information and care, feeling about adoption) based on focus group and cognitive interview feedback. The response scale used for the 46 potential RCAC scale items was a five-point Likert scale ranging from 1 = “Strongly disagree” to 5 = “Strongly agree.”

We included the following four instruments to assess overall well-being:

*Medical Outcomes Study (MOS) social support survey* The MOS social support survey is a nine-item self-report measure designed to assess four types of social support (i.e., emotional/informational, tangible, affectionate, and positive social interaction) [41]. The survey asks participants to rate how often they have the following types of support if they need it on a five-point scale ranging from 1 = “None of the time” to 5 = “All of the time.” The total scores range from 0 to 45, with higher scores indicating greater levels of social support. The MOS social support survey is an established reliable and valid measure of social support ( $\alpha = 0.93$ ) [41] and has been used with cancer patients and survivors [42–45]. We found excellent reliability in this sample ( $\alpha = 0.93$ ).

*Satisfaction With Life Scale (SWLS)* The SWLS is a five-item tool developed to measure an individual’s satisfaction with her own life. Participants are asked to rate how much they agree/disagree with each item on a seven-point Likert scale, ranging from 1 = “Strongly disagree” to 7 = “Strongly agree”; higher scores on the scale indicate better satisfaction with one’s life [46]. The SWLS has been shown to have strong psychometric properties; alpha coefficients have been shown to range from 0.79 to 0.89 [47, 48], and alpha was excellent in this sample

( $\alpha = 0.93$ ). The SWLS has been used to assess subjective well-being among the normal population [49, 50] as well as in studies with young adult female cancer survivors [7, 51–53].

*Health Related Quality of Life Assessment (HRQOL-4)* The Health Related Quality of Life (HRQOL-4) is composed of four brief questions regarding self-rated health, physically unhealthy days, mentally unhealthy days, and activity-limitation days [54, 55]. The HRQOL-4 was developed by the Centers for Disease Control and Prevention for public health surveillance to measure impaired HRQOL and has been included in the Behavioral Risk Factor Surveillance System since 1993 and the National Health and Nutrition Examination Survey since 2000. It has been shown to be a valid and reliable measure of health-related quality of life [49, 56–58] and has been used in studies with cancer survivors [59–61]. We found acceptable reliability in this sample ( $\alpha = 0.73$ ).

*Patient Health Questionnaire Assessment of Depression (PHQ-9)* The depression scale of the Patient Health Questionnaire (PHQ-9) is a nine-item self-administered assessment tool used by health professionals and clinicians to diagnose depression. Each item of the PHQ-9 was based on the diagnostic criteria of the Diagnostic and Statistical Manual Fourth Edition. Respondents are asked to rate how often they have been bothered by the following problems over the past 2 weeks with response categories ranging from 0 “Not at all” to 3 “Nearly every day.” Higher scores are indicative of more severe depression; scores of 5, 10, 15, and 20 correspond to mild, moderate, moderately severe, and severe depression, respectively. The PHQ-9 has been shown to have adequate construct validity and criterion validity [62, 63] and has been used in studies with cancer patients and survivors [64, 65]. The internal consistency for this sample was good ( $\alpha = 0.86$ ).

### Data analysis

Initial analyses of survey data included data cleaning, identification of outliers, and examining means and distributions of the 46 potential RCAC scale items. In the initial phase of item reduction, we discarded nine items with extreme means, skewed or limited variances, and confusing wording. Items eliminated did not represent any content areas that were not represented in the remaining 37 items. Examples of items eliminated include: “It makes me sad to think that I might not be able to have any (more) children” and “I feel confident that my children would be healthy.” We subjected the remaining 37 potential items to principal components analysis (PCA) to identify the underlying factor structure and additional items for elimination. Prior to rotation, we used minimum average partial [66] in conjunction with a review of Eigenvalues and a Scree plot, to determine the number of factors to retain. We used oblique rotation (Promax) to allow for expected factor

correlations. In the first iteration, we removed items with loadings less than 0.60 and those that cross-loaded on a secondary factor at 0.30 or higher. We subjected the remaining 26 items to a second PCA and selected the three top loading items from each factor to include in the final 18-item scale. We calculated internal consistency of total and subscale scores as coefficient alpha, with a minimum value of 0.70 being acceptable [67]. This process allowed us to examine a large number of variables representing different dimensions within a set of items and to reduce the number of items to create a brief scale feasible for clinical and research application. All potential reproductive concerns dimensions raised by focus group participants in Phase 1 are represented in the final scale.

### Phase 3: hypothesis generation

We made predictions for construct validity based on existing literature and our prior research [8, 15]. Using the known-groups approach, we evaluated differences in RCAC scores between desire for a child (yes vs. no or don't know) and importance of biological children (very important vs. other categories). We hypothesized that participants who reported that they wanted to have a child and those for whom biological children were very important would have higher mean scores. We used analysis of variance to evaluate differences in RCAC scores across these groups. We evaluated convergent and divergent validity by evaluating the relationship between RCAC scores and scores from four validated instruments. We hypothesized low to moderate negative statistical associations with the MOS Social Support Survey [41] and SWLS [46] and positive associations with the CDC HRQOL-4 (unhealthy days) [54] and PHQ-9 [63]. The constructs represented by these measures were expected to be related but conceptually distinct from that of reproductive concerns. We evaluated Pearson product-moment correlations to assess the magnitude and direction of associations between RCAC scores and those from the MOS, SWLS, CDC HRQOL-4, and PHQ-9. We used analysis of variance to conduct exploratory analyses comparing RCAC total and subscale scores across categories of age, race/ethnicity, relationship status, and reproductive history. For all statistical tests, a two-tailed test with alpha 0.05 was considered significant. All data were analyzed using the statistical software SAS, version 9.2 [68]. The study was approved by the University of California San Diego Institutional Review Board.

## Results

### Sample characteristics

Two hundred twenty-nine YA female cancer survivors completed the online informed consent procedure, and 204 (89 %)

of those went on to complete the survey. Participants were 28.3 (SD=4.5) years on average and most were White (80 %). The most common cancer diagnoses were breast (17 %), Hodgkin's lymphoma (15 %), leukemia (13 %), thyroid (10 %), non-Hodgkin's lymphoma (8 %), and brain (7 %) and soft tissue cancers (6 %), in addition to 19 other cancer types. Participants had been diagnosed between the ages of infancy and 34 years (mean=22.7, SD=7.0), and the average duration of survivorship was 5.7 years (SD=5.4). Most participants (65 %) were fewer than 5 years post-diagnosis at the time of the survey and either married or in a committed relationship (60 %). At the time of the survey, almost all participants (95 %) reported having some type of health insurance coverage; 53 % were employed full-time; 15 % were employed half-time, and 17 % were students (Table 1).

### Factor structure

Minimum average partial [66], in conjunction with a review of Eigenvalues and a Scree plot, revealed a six-factor solution. Using oblique (Promax) rotation over three iterations with the 37 potential scale items, we excluded 19 items because either the magnitudes of the item loadings did not meet the predetermined cut point of 0.60 or greater or because the items loaded on a secondary factor at 0.30 or greater. Table 2 shows the factor loadings for the 18 items that were retained for the final PCA. The six factors accounted for 65.5 % of the total variance. The lowest factor loading was 0.59, with all other loadings in excess of 0.69. The internal consistency of the total RCAC scale was good ( $\alpha=0.82$ ). Internal consistencies for each of the six three-item subscales were in the good or acceptable range: Fertility potential (factor 1),  $\alpha=0.86$  (mean=3.59, SD=1.09); Partner disclosure of fertility status (factor 2),  $\alpha=0.88$  (mean=3.15, SD=1.22); Child's health (factor 3),  $\alpha=0.88$  (mean=3.66, SD=1.17); Personal health (factor 4),  $\alpha=0.83$  (mean=3.32, SD=1.13); Acceptance (factor 5),  $\alpha=0.82$  (mean=2.70, SD=0.97); and Becoming pregnant (factor 6),  $\alpha=0.78$  (mean=3.09, SD=0.95). Table 2 also shows mean scores for each item and communalities, which were all greater than 50 %.

Table 3 shows correlations between factors. Table 4 shows mean total RCAC scale scores and subscale scores for the total sample by parenthood desires and demographic characteristics. In support of our a priori hypothesis, following the known groups approach, we found that women who wanted to have a baby had higher mean total scores than those who did not (3.34 vs. 2.99,  $p<0.001$ ). Those for whom having a biological child was very important also had higher mean total scores than those who said that having a biological child was less important (3.37 vs. 3.13,  $p<0.05$ ). In our exploratory analyses of RCAC scale scores across demographic characteristics, we found lower total scores for survivors who were married or in a committed relationship as compared with those who were not (3.17 vs. 3.38,

**Table 1** Sample characteristics  
(*N*=204)

	Age, 18–29 years <i>n</i> =110 <i>n</i> (%)	Age, 30–35 years <i>n</i> =94 <i>n</i> (%)
Demographics		
Race		
White	88 (80.0)	75 (79.8)
Non-white	22 (20.0)	19 (20.2)
Hispanic/Latina ethnicity	10 (9.1)	9 (9.6)
Married or committed relationship*	58 (52.7)	64 (68.1)
Biological child(ren)**	10 (9.1)	25 (26.6)
Education**		
High school graduate	40 (36.4)	17 (18.1)
College or graduate degree	70 (63.6)	77 (81.9)
Occupation status*		
Full time	49 (44.6)	58 (61.7)
Part time	17 (15.5)	14 (14.9)
Student	27 (24.6)	7 (7.5)
Other	17 (15.5)	15 (16.0)
Cancer characteristics and treatment		
Life stage at diagnosis**		
Childhood (≤14 years)	20 (18.2)	6 (6.4)
Adolescence (15–19 years)	22 (20.0)	2 (2.1)
Young adulthood (20–35 years)	68 (61.8)	86 (91.5)
Cancer type**		
Breast	8 (7.3)	27 (28.7)
Hodgkin's lymphoma	17 (15.5)	13 (13.8)
Leukemia	21 (19.1)	6 (6.4)
Thyroid	8 (7.3)	13 (13.8)
Non-Hodgkin's lymphoma	11 (10.0)	6 (6.4)
Brain	10 (9.1)	2 (2.1)
Soft tissue sarcoma	10 (9.1)	2 (2.1)
Other <sup>a</sup>	25 (22.7)	25 (26.6)
Cancer treatment		
Chemotherapy	88 (80.0)	68 (72.3)
Radiation	56 (50.9)	48 (51.1)
Hematopoietic cell transplant	14 (12.7)	8 (8.5)
Duration of survivorship (years)		
1–4	70 (63.6)	62 (66.0)
5–9	24 (21.8)	18 (19.2)
≥10	16 (14.6)	14 (14.9)

\**p*<0.05, \*\**p*<0.01<sup>a</sup>Nineteen other cancer types represented

*p*<0.05). Total scores were also lower for those who had college or graduate degrees as compared with those who did not (3.18 vs. 3.42, *p*<0.05). There were no differences in mean total scores across age category or other demographic characteristics.

We observed low to moderate correlations in the expected direction between the total RCAC scale score and four related but conceptually distinct measures: social support (*r*=−0.25), health-related quality of life (*r*=0.32), satisfaction with life (*r*=−0.32), and depression (*r*=0.37) (all with *p*<0.001). As hypothesized, total scores were positively associated with

depression and health-related quality of life (higher scores indicate poorer quality of life) and negatively associated with social support and satisfaction with life. The patterns support the construct validity of the RCAC scale.

## Discussion

YA cancer survivors have significant concerns about fertility and parenthood issues that extend beyond biologic fertility

**Table 2** Factor analysis of the multidimensional Reproductive Concerns After Cancer Scale (RCACS) (18 items), Promax rotation, six-factor solution for total sample (Cronbach's  $\alpha=0.82$ )

Item (item no.)	Mean (SD)	Factor 1 Fertility potential ( $\alpha=0.91$ )	Factor 2 Partner disclosure ( $\alpha=0.88$ )	Factor 3 Child's health ( $\alpha=0.88$ )	Factor 4 Personal health ( $\alpha=0.83$ )	Factor 5 Acceptance ( $\alpha=0.82$ )	Factor 6 Becoming pregnant ( $\alpha=0.78$ )	$h^2$
I am afraid I won't be able to have any (more) children (6)	3.64 (1.23)	<b>0.86</b>	0.04	0.00	0.01	-0.02	0.03	0.76
I am worried about my ability to get pregnant (again) (10)	3.53 (1.19)	<b>0.81</b>	-0.01	-0.03	0.04	0.08	0.02	0.74
I am concerned that I may not be able to have (more) children (14)	3.59 (1.16)	<b>0.87</b>	-0.00	-0.00	-0.02	-0.01	-0.04	0.74
I worry about telling my (potential) spouse/partner that I may be unable to have children (36)	3.08 (1.39)	-0.01	<b>0.82</b>	-0.04	-0.04	-0.01	-0.09	0.71
I am concerned that my (potential) spouse/partner will be disappointed if I can't get pregnant (38)	3.38 (1.31)	0.14	<b>0.77</b>	0.06	-0.04	-0.09	-0.04	0.63
The thought of telling my (potential) spouse/partner that I may be unable to have children makes me uncomfortable (46)	2.99 (1.38)	-0.08	<b>0.88</b>	-0.01	0.07	0.07	-0.02	0.78
I am worried about passing on a genetic risk for cancer to my children (21)	3.68 (1.35)	0.02	-0.02	<b>0.89</b>	-0.04	-0.03	0.02	0.76
I am worried about how my family history might affect my children's health (22)	3.70 (1.28)	-0.02	0.02	<b>0.79</b>	0.00	-0.03	0.06	0.67
I am afraid my children would have a high chance of getting cancer (24)	3.61 (1.25)	-0.03	-0.00	<b>0.73</b>	0.19	0.06	-0.06	0.69
I am scared of not being around to take care of my children someday (25)	3.76 (1.23)	-0.01	-0.03	0.12	<b>0.72</b>	0.12	0.02	0.61
Having (more) children will make me more nervous about getting cancer again (26)	3.21 (1.30)	0.09	-0.05	0.04	<b>0.71</b>	-0.06	-0.01	0.54
I am cautious about having (more) children because I might not be around to raise them (27)	3.00 (1.36)	-0.06	0.07	-0.03	<b>0.83</b>	-0.10	0.01	0.73
I can accept it if I'm unable to have (more) children (4) <sup>a</sup>	2.52 (1.14)	0.11	-0.02	0.00	-0.04	<b>0.69</b>	-0.04	0.57
I will be happy with life whether or not I have (more) children someday (11) <sup>a</sup>	2.54 (1.12)	-0.07	-0.08	-0.07	0.05	<b>0.79</b>	0.07	0.55
I will feel content if I do not have (more) children (13) <sup>a</sup>	3.02 (1.14)	0.06	0.11	0.07	-0.06	<b>0.73</b>	-0.06	0.65
I am overwhelmed by thought of trying to get pregnant (again) (33)	3.03 (1.14)	0.11	-0.04	0.05	0.01	-0.03	<b>0.75</b>	0.61
I worry that getting pregnant (again) would take too much time and effort (34)	2.96 (1.16)	-0.13	0.01	-0.01	-0.05	-0.09	<b>0.76</b>	0.54
It is stressful to think about trying to get pregnant (again) (45)	3.28 (1.13)	0.09	0.09	-0.01	0.07	0.17	<b>0.59</b>	0.53
Variance explained by each factor (%)	-	12.7	11.9	11.7	10.3	10.1	8.7	-

Response scales range 1–5

<sup>a</sup> Reverse-coded, higher scores indicate lower acceptance of not having children

potential. We aimed to develop a reliable and valid scale to measure the breadth and depth of reproductive concerns of young adult women who have survived cancer. These concerns are captured by the multidimensional, 18-item RCAC scale. Items effectively measured the factors, as shown by the loadings, and were well defined by the solution, as indicated by the communalities. Internal consistency values for the total

scale and all subscales were in the acceptable to good range, offering support for the scale's reliability. The scale demonstrated a meaningful and strong factor structure and expected associations with measures of social support, satisfaction with life, health-related quality of life, and depression. As hypothesized, total RCAC scores were highest among those who reported wanting to have a baby and those who said that

**Table 3** Factor correlations

Factor	1	2	3	4	5	6
Fertility potential	–	0.32**	0.01	–0.01	0.45**	0.24**
Partner disclosure		–	0.10	0.10	0.25**	0.33**
Child's health			–	0.52**	–0.10	0.22**
Personal health				–	–0.14*	0.32**
Acceptance					–	0.03
Becoming pregnant						–

\* $p < 0.05$ , \*\* $p < 0.01$ 

having a biological child was very important. These findings support the construct validity of the scale. Each subscale assesses unique but related reproductive concerns, including concerns about fertility potential, discussing potential fertility problems with a spouse or partner, children's health, personal health, acceptance of possibly not being able to have children, and trying to become pregnant. While additional research is needed to verify clinically meaningful cut-points for the scale, a respondent with a mean score of four or greater (range, 1–5) on any particular domain or on the total scale, is self-reporting a meaningful level of concern that indicates a need for further attention. The RCAC scale taps psychosocial, developmental, and health-related reproductive concerns that are meaningful for YA female cancer survivors. Each subscale indicates a type of concern that could be addressed clinically to promote well-being and long-term quality of life.

The RCAC scale was developed with input from YA cancer survivors and is appropriate for use across the 18–35-year age range. Our study was designed to identify and measure the concerns of survivors in this age range, and the scale needs to be validated for use with survivors above age 35 years, who may have different concerns. In exploratory analyses, participants younger than 30 years did not have significantly different total RCAC scores than those over the age of 30 years. Younger participants were more concerned about disclosing potential fertility problems with their (potential) partner but had similar scores across other subscales. Higher disclosure concerns could be explained by the fact that younger participants may be less likely to be in a committed relationship or to have already had a conversation with their partner. Those who had already had a child and those in a married or committed relationship were less concerned about disclosure, potentially because they and their partner already knew about their fertility status. Our results suggest that younger survivors and those not in committed relationships may need additional guidance on discussing fertility and future parenthood options with their partners. We also identified some differences across reproductive history characteristics. For example, those with a history of miscarriage had higher total RCAC scores than those without and were more concerned about their (potential) children's health, their personal health, and becoming pregnant. Those with a history of infertility

did not have higher total scores but were less accepting of the possibility of not having children and were less worried about partner disclosure. These results provide some insight into the diverse range of reproductive concerns among young survivors, but further research is needed to delineate groups with the highest level of concerns across each domain, as well as to identify the most effective approach to addressing those concerns.

Identifying and addressing concerns about survivors' (potential) children's health and fertility potential are two additional examples of the scale's potential clinical utility. The subscale measuring survivors' concerns about their (potential) children's health indicates concerns about risks related to genetics, family history, and increased cancer risk. These concerns were also apparent during focus group discussions, even among participants who had no known genetic or family history risks. For example, participants raised concerns about potential and unknown risks that could affect their future children related to their cancer diagnosis and treatment. Women who are concerned about this issue may benefit from further discussion with an obstetrician/gynecologist or genetic counselor. The subscale measuring survivors' concerns about fertility potential indicates the level of concern about inability to have biological children in the future. This was a primary concern discussed during focus groups, in which many participants reported uncertainty about their fertility status and discussed an underlying fear about discovering that their fertility had been compromised by their treatment. This concern could be addressed through reproductive health screening (e.g., ovarian reserve testing) and referral to a reproductive endocrinologist or gynecologist specializing in treatment of cancer survivors.

Our data support the validity of the RCAC scale as a web-based self-report measure to assess young adult cancer survivors' (age, 18–35 years) reproductive concerns. Potential research applications include measuring, overall and across each domain, the level of reproductive concerns among cancer survivors of varying ages, cancer types, life circumstances, and other characteristics to determine groups at highest risk. Another potential area of future research is an assessment of how reproductive concerns change over time and what factors are associated with that change, as well as whether the level of concerns is associated with psychosocial outcomes such as depression and health-related quality of life. These are important steps toward understanding and addressing the long-term reproductive health needs of young women who have survived cancer.

The RCAC scale is in the early stages of development and has limitations. Future assessment of the scale should include test–retest reliability and predictive validity in a prospective sample. While the present sample was diverse across many characteristics, including age and cancer type, survey participants were mostly White and well-educated, limiting our ability to generalize our findings. The potential scale items were developed with feedback from racially and ethnically



**Table 4** Mean overall scores and subscale scores by parenthood desires, demographics, and reproductive history

	No. (%)	Mean (SD)						
		Total score	Factor 1 Fertility potential	Factor 2 Partner disclosure	Factor 3 Child's health	Factor 4 Personal health	Factor 5 Acceptance <sup>a</sup>	Factor 6 Becoming pregnant
Sample combined	204 (100)	3.25 (1.09)	3.59 (1.09)	3.15 (1.22)	3.66 (1.17)	3.32 (1.13)	2.70 (0.97)	3.09 (0.95)
Parenthood desires								
Wants a baby								
Yes	150 (73.5)	3.34 (0.57)**	3.94 (0.87)**	3.28 (1.20)*	3.65 (1.13)	3.19 (1.02)*	2.94 (0.93)**	3.06 (0.95)
No	54 (26.5)	2.99 (0.65)	2.62 (1.08)	2.80 (1.23)	3.70 (1.29)	3.68 (1.32)	2.00 (0.73)	3.17 (0.95)
Biological child very important								
Yes	103 (50.5)	3.37 (0.54)*	3.92 (0.90)**	3.16 (1.18)	3.76 (1.10)	3.32 (1.05)	3.07 (0.95)**	2.99 (0.99)
No	101 (49.5)	3.13 (0.66)	3.25 (1.18)	3.13 (1.27)	3.56 (1.23)	3.32 (1.20)	2.31 (0.84)	3.20 (0.89)
Demographics								
Current age (years)								
18–29	110 (53.9)	3.30 (0.60)	3.66 (1.03)	3.38 (1.20)*	3.76 (1.13)	3.22 (1.14)	2.73 (0.97)	3.07 (0.97)
30–35	94 (46.1)	3.19 (0.62)	3.50 (1.17)	2.88 (1.20)	3.55 (1.21)	3.45 (1.10)	2.66 (0.98)	3.12 (0.92)
Race								
White	163 (79.9)	3.23 (0.62)	3.54 (1.14)	3.14 (1.25)	3.63 (1.16)	3.30 (1.12)	2.70 (0.95)	3.09 (0.94)
Non-white	41 (20.1)	3.32 (0.58)	3.76 (0.90)	3.19 (1.12)	3.78 (1.20)	3.42 (1.16)	2.67 (1.06)	3.12 (0.99)
Hispanic/Latina ethnicity								
Yes	19 (9.3)	3.46 (0.56)	3.67 (1.07)	3.49 (1.41)	3.82 (1.04)	3.70 (1.05)	2.89 (1.28)	3.19 (1.01)
No	185 (90.7)	3.23 (0.61)	3.58 (1.10)	3.12 (1.20)	3.64 (1.18)	3.28 (1.13)	2.68 (0.94)	3.08 (0.94)
Partnered relationship								
Yes	122 (59.8)	3.17 (0.62)*	3.59 (1.14)	2.66 (1.19)**	3.67 (1.22)	3.41 (1.08)	2.66 (0.99)	3.03 (1.00)
No	82 (40.2)	3.38 (0.58)	3.59 (1.03)	3.87 (0.86)	3.65 (1.14)	3.19 (1.18)	2.75 (0.94)	3.19 (0.86)
Highest degree								
High school	57 (27.9)	3.42 (0.62)*	3.71 (1.01)	3.54 (1.03)**	3.78 (1.22)	3.50 (1.20)	2.68 (1.00)	3.32 (0.95)*
College/graduate	147 (72.1)	3.18 (0.60)	3.54 (1.26)	3.00 (1.26)	3.61 (1.15)	3.25 (1.09)	2.70 (0.96)	3.01 (0.94)
Occupation status								
Full time	107 (52.4)	3.26 (0.61)	3.76 (1.02)	3.09 (1.23)	3.55 (1.19)	3.30 (1.13)	2.76 (1.00)	3.08 (0.94)
Part time	31 (15.2)	3.25 (0.58)	3.48 (1.08)	2.87 (1.28)	3.78 (1.21)	3.45 (1.15)	2.78 (0.91)	3.15 (0.94)
Student	34 (16.7)	3.25 (0.58)	3.51 (1.10)	3.43 (1.28)	3.83 (1.01)	3.02 (0.90)	2.60 (1.00)	3.08 (0.85)
Other	32 (15.7)	3.24 (0.67)	3.20 (1.27)	3.33 (1.22)	3.71 (1.21)	3.60 (1.28)	2.49 (0.90)	3.10 (1.12)
Reproductive history								
Previous live birth								
Yes	35 (17.2)	3.22 (0.49)	3.25 (1.07)	2.56 (0.95)*	4.03 (1.04)	3.95 (1.02)**	2.50 (0.81)	3.01 (1.03)
No	169 (82.8)	3.26 (0.63)	3.65 (1.09)	3.26 (1.24)	3.59 (1.18)	3.21 (1.11)	2.73 (1.00)	3.11 (0.94)
Previous miscarriage								
Yes	14 (6.9)	3.67 (0.54)**	4.10 (1.30)	3.17 (1.06)	4.31 (0.83)*	3.93 (0.97)*	2.93 (1.26)	3.60 (0.83)*
No	190 (93.1)	3.22 (0.60)	3.55 (1.08)	3.15 (1.24)	3.61 (1.18)	3.23 (1.13)	2.68 (0.95)	3.06 (0.95)
Normal menstruation <sup>b</sup>								
Yes	122 (61.6)	3.27 (0.61)	3.60 (1.06)	3.13 (1.25)	3.85 (1.10)**	3.33 (1.11)	2.63 (0.94)	3.07 (0.95)
No	76 (38.4)	3.24 (0.63)	3.61 (1.17)	3.23 (1.20)	3.38 (1.24)	3.30 (1.18)	2.82 (1.02)	3.13 (0.99)
History of infertility								
Yes	15 (7.4)	3.21 (0.40)	3.80 (1.20)	2.44 (0.71)*	3.13 (1.26)	3.42 (1.06)	3.24 (1.01)*	3.22 (0.87)
No	189 (92.6)	3.25 (0.63)	3.57 (1.09)	3.21 (1.24)	3.70 (1.15)	3.31 (1.13)	2.65 (0.96)	3.08 (0.96)

Response scales range 1–5

\* $p < 0.05$ , \*\* $p < 0.01$ <sup>a</sup> Reverse-coded, higher score indicates lower acceptance of not having children<sup>b</sup> Data missing for six participants. Defined as ten or more bleeding episodes in the previous 12 months

diverse focus group participants, so we expect to have captured a culturally competent set of reproductive concerns items. It is possible, however, that a more racially and ethnically diverse study population in Phase 2 would have resulted in different factor loadings. Additional studies are needed to validate the scale for use with specific racial and ethnic groups. We also did not find any difference in RCAC total or subscale scores across racial or ethnic groups, but potential disparities in reproductive concerns and validity of the scale should be further explored in a larger sample. Our recruitment strategy relied heavily on announcements through social media outlets, and therefore, the sample may not be representative. Also, most participants expressed the desire to be a parent, so the scale may not capture reproductive concerns among women who do not want to have children. The scale may also be appropriate for younger adolescent survivors but that needs to be established in future studies. Future work should further explore how reproductive concerns vary by demographics, life stage at cancer diagnosis, duration of survivorship, cancer characteristics, and treatment type to identify high-risk populations in need of reproductive-related support and information.

Reproductive concerns are very important to many young survivors and associated with poorer quality of life, depressive symptoms, and distress [14–16]. Patient informational needs regarding fertility and parenthood issues are not being adequately addressed among YA survivors, a medically underserved population in which these issues may be particularly important [10, 29–32]. Our results suggest that the RCAC scale is a reliable and valid measure of reproductive concerns among YA female cancer survivors. The multidimensional RCAC scale identifies a range of concerns that are not included in the one previously existing scale and has significant potential for future clinical and research applications. Identifying these concerns as well as understanding how they may change over time, vary by population, and relate to both long-term psychosocial and physical health outcomes for cancer survivors are an essential step in meeting the long-term reproductive health needs of young women who have survived cancer.

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