

# Cultural adaptation and psychometric evaluation of the Swedish version of the Reproductive Concerns After Cancer (RCAC) scale

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## Short report

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# Abstract

**Background** Reproductive concerns are common among young cancer survivors and include worries related to different aspects of fertility and parenthood. The Reproductive Concerns After Cancer (RCAC) scale is an 18-item scale with six dimensions, developed to capture a variety of such concerns. The aim of the present study was to culturally adapt the RCAC scale into Swedish and evaluate its psychometric properties among young women with cancer experience.

**Methods** The RCAC was forward-translated from English into Swedish and assessed for cultural adaptation based on a two-panel approach followed by cognitive interviews with representatives of the target group. For the psychometric evaluation, a Swedish cohort of 181 young adult breast cancer survivors completed a survey including the RCAC scale approximately 1.5 years post-diagnosis. Investigation of the psychometric properties included analyses of construct validity (confirmatory factor analysis and convergent validity), data quality (score distribution, floor and ceiling effects), reliability (Cronbach's  $\alpha$ ) and known-groups validity based on current child wish.

**Results** The breast cancer survivors had a mean age of 36.5 (SD 4.1) years and a third of them expressed a current wish for (additional) children. The confirmatory factor analysis yielded a satisfactory fit (RMSEA 0.08, SRMR 0.09, CFI 0.92). Convergent validity was demonstrated by a negative correlation with moderate effect size (-0.361) between the RCAC total score and the emotional functional scale of EORTC QLQ-C30. Reliability was in the acceptable range ( $\alpha$ = 0.78-0.92) for four of the dimensions, nearly acceptable for Personal health ( $\alpha$ , 0.68) and poor for Becoming pregnant ( $\alpha$ = 0.54). Known-groups validity was indicated by significantly higher RCAC mean score differences (MD), reflecting more concerns, among women with a certain (MD 4.56 [95% CI 3.13 to 5.99]) or uncertain (MD 3.41 [95% CI 1.68 to 5.14]) child wish, compared to those with no wish for (additional) children.

**Conclusion** The Swedish RCAC scale demonstrated satisfactory reproducibility of the original RCAC scale with acceptable convergent and known-groups validity, but satisfactory reliability was not achieved for all dimensions. The Swedish RCAC scale exhibits adequate psychometric properties and could be useful for assessment of reproductive concerns in young adult female cancer survivors in Sweden.

## Background

A large number of individuals in the age bracket 18–39, defined as young adults, are diagnosed with cancer worldwide. In the United States alone, around 60,000 young adults are diagnosed with cancer yearly (1) and, correspondingly in Sweden, around 2,000 young adults face a cancer diagnosis every year (2). The cancer itself, or being exposed to surgical and/or gonadotoxic treatments may result in temporary or permanent infertility, or sub-fertility in young adult survivors (3), many of whom may not have had the possibility to start or complete their family prior to their cancer diagnosis. Young adult cancer survivors report a number of reproductive concerns and fertility-related distress after treatment, including worry regarding the ability to have children in the future, fears about recurrence, their child's

health and their own health (4, 5). Reproductive concerns may also affect other areas of psychosocial functioning (4, 6). Among female cancer survivors, a wish for (additional) children has shown to be associated with more worries about infertility (7) and higher levels of reproductive concerns were found to be associated with poorer quality of life and more depression (8).

To capture the full range of reproductive concerns following cancer the multidimensional Reproductive Concerns After Cancer (RCAC) scale was developed for use in young adult female survivors (9). The scale has shown satisfactory construct validity and internal consistency among women aged 18–44 treated for different types of cancer in the United States (9, 10). Outside the US context, the RCAC scale was recently translated and culturally adapted into Chinese and demonstrated suitable psychometric properties for evaluation of reproductive concerns in young female patients with cancer (11).

The aim of the present study was to culturally adapt the RCAC scale into Swedish and evaluate its psychometric properties among young women with cancer experience.

## Methods

### The RCAC Scale

The RCAC scale consists of 18 items that constitute six dimensions: Fertility potential, Partner disclosure, Child's health, Personal health, Acceptance and Becoming pregnant. Each dimension has three items with responses scored on a five-point scale (ranging from 1=Strongly disagree to 5=Strongly agree), with high scores indicate higher levels of reproductive concerns (9).

### Swedish translation and cultural adaptation of the Swedish RCAC Scale

For the purpose of use in a study from our research group (12), the original RCAC scale was evaluated for its relevance in measuring fertility concerns in a Swedish context. To achieve this, the scale was forward translated into Swedish based on the two-panel approach and further assessed for cultural adaptation (13). The first step of the cultural adaptation comprised assessment of the appropriateness of the translated scale by one bilingual expert panel and by one lay panel. As a next step, in order to assess if the scale was perceived as relevant and acceptable, focus group discussions and cognitive interviews were performed with representatives of the target population. The process of the cultural adaptation was coordinated by an experienced coordinator to ensure none of the parameters were neglected and to maintain the quality of the adaptation.

#### Forward translation by bilingual expert panel

The RCAC scale was translated from English to Swedish by two researchers who were native Swedish speakers and well-versed in English. The first translator (T1) had extensive research knowledge in the field of fertility and cancer. The second translator (T2) coordinated the translation and was experienced in instrument translation and adaptation, but was not knowledgeable in the research fields of fertility and cancer. Both researchers had broad experience of clinical work with diverse patient groups. Following

individually performed translations of the scale, T1 and T2 discussed discrepancies between the two versions. As a next step, they consulted the principal investigator of the original English version of the RCAC to discuss and clarify the intended conceptual meaning of the scale and specific items. Subsequently, two experts in the field of psychosocial oncology (native Swedish speakers) thoroughly scrutinised both versions and discussed a few remaining issues regarding the translation. As a result, a consensus version of the Swedish version of the RCAC was created. Cultural adaptation included changing the use of “spouse/partner” in the three items of the dimension Partner disclosure to “partner”, as this was deemed more appropriate for use in the Swedish context where it is common for two adults to live together without being married.

#### Lay panel assessment

For evaluation of the translated version of the scale two lay panels were recruited through personal contacts and local advertisements. The panel members were 3 women and 4 men between 18-41 years old; three had secondary education and four had higher education. Two had children and none of the panel members had been diagnosed with cancer. Panel members were compensated with cinema tickets for their participation. The lay panels were only provided with the Swedish version of the scale, as suggested (13). The lay panel members were instructed to go through all parts of the RCAC scale, including instructions, items and response options. Everyone read each item, then discussed how they perceived the issue and whether there were any alternative translations. Based on the assessment by the lay panels minor changes in wording were made. The main role of the lay panels was to produce a version that was easy to understand for the average Swedish speaking person. The assessment was led by a coordinator who also participated (T2) in the expert panel.

#### Patient/Target group assessment

The patient/target group included 5 women and 3 men (aged 20-41) who had been treated for cancer. The target group members came from different geographical areas in Sweden and all had secondary or higher education. They evaluated the translated RCAC scale for face validity i.e., if the items and response alternatives were relevant and acceptable. Some concerns were expressed regarding the suitability and relevance of the scale for patients in their late teens, which led us to conducting cognitive interviews as described below. The target group members were compensated for their travel costs and time spent.

#### Cognitive interviews

Cognitive interviews were performed individually with 3 young individuals (1 female aged 18 years and 2 males aged 17 years) currently being treated for cancer. The participants filled in the Swedish RCAC scale completely themselves and were then interviewed on their experience of filling the form. Following this, the participants were asked to give their input on the individual items in the scale. The most important

purpose of the interviews was to ensure that the scale was suitable for teenagers with cancer. Another purpose was to get a final input on the instrument regarding questionnaire structure (including layout and instructions), items and language.

## **Psychometric evaluation**

### Participants and procedure

A detailed description of the study participants and procedure is presented elsewhere (12). Briefly, a sample of 301 women consecutively diagnosed with invasive breast cancer at age 18-39 years were identified from the Swedish National Quality Register for Breast Cancer. Data collection was conducted by means of a comprehensive postal survey approximately 1.5 years post-diagnosis. Ethical approval for the study was obtained from the Regional Ethical Review Board in Stockholm, Sweden (Ref No: 20131746-31/4).

### Additional Measures

The survey completed by the participants comprised several patient reported outcome measures. For the purpose of the psychometric evaluation of the Swedish version of the RCAC, the Emotional Function scale of the EORTC QLQ-C30 version 3.0 (14) and a study-specific item regarding current wish to have (additional) children (response alternatives: Yes, Uncertain, No) were used from the survey.

## **Statistical analysis**

Statistical analysis was performed using SPSS statistics for Windows, version 24 (IBM Corp., Armonk, N.Y., USA) and IBM® SPSS® Amos, version 25. For all statistical tests, the level of statistical significance was defined as  $p < 0.05$ .

Construct validity was ascertained using Confirmatory factor analysis (CFA) and convergent validity. CFA was performed to determine the adequacy of the original six-factor of the RCAC on our sample data (9). Missing values for single items ( $n=15$ ) was handled by imputing the mean of the other two items of the same individual in the same dimension. Those with an entire missing scale ( $n=7$ ) and those when more than two items in a dimension were missing ( $n=1$ ) were excluded. Standardized factor loadings and model fit were determined from the CFA. Standardized factor loadings of  $\geq 0.4$  were considered as acceptable as determined from the CFA (15). Model fit was estimated by two absolute indices of overall model fit 1) Root mean square error of approximation ((RMSEA) and 2) Standardized root mean residual ((SRMR) and one relative index of model fit compared to the null model 3) Comparative fit index (CFI). The acceptable thresholds for these indices were defined as RMSEA: 0.05 - 0.08, SRMR:  $< 0.10$  and CFI:  $> 0.90$  according to Kline's guidelines (16). The degrees of freedom were reported, but were not considered as an indicator of model fit owing to their restrictiveness due to being sensitive to sample size (17). Convergent validity was assessed by calculating the Pearson correlation coefficient for the mean score of

the Swedish RCAC scale and the Emotional Function scale of the EORTC QLQ-C30. A moderate magnitude of  $> 0.3$  was considered acceptable (18, 19).

Data quality was assessed using mean scores, standard deviations (SD) and percentages of respondents scoring the minimum (floor) and maximum (ceiling) possible scores were calculated. Floor and ceiling effects were considered present if  $>15\%$  rated at the lowest (floor) and highest (ceiling) scores (20).

Reliability was assessed by calculating the internal consistency of the six dimensions using Cronbach's  $\alpha$  coefficient. A Cronbach's  $\alpha$  value of  $\geq 0.70$  was regarded as acceptable (21).

Known-groups validity was assessed by comparing groups expected to differ with regard to reproductive concerns. A one-way ANOVA with post-hoc comparisons using the Tukey test was conducted to compare the mean score of the Swedish RCAC scale of three groups with a certain, uncertain or no wish for (additional) children.

## Results

### Sample characteristics

Of 301 eligible women, 181 completed the survey (response rate 60%). Demographic and clinical characteristics of the participants are presented in detail elsewhere (12). Briefly, mean age was 36.5 (SD 4.1, range 23-42), a majority had children (77%) and were in a current partner relationship (87%). A wish for (additional) children was expressed by 36% of the women, 20% were uncertain and 44% had no current child wish.

### Construct validity

#### Confirmatory factor analyses

The CFA was performed on 177 participants and provided an  $X^2$  value of 246.543 (degrees of freedom =120;  $p < 0.001$ ). The CFA provided an RMSEA of 0.08, SRMR value of 0.09 and a CFI of 0.92 indicating a satisfactory fit. Standardized factor loading estimates ranged from 0.43 to 0.94 and were above the acceptable factor loading cut-off (Figure 1). All standardized factor loadings were statistically significant ( $p < 0.01$ ) for all six of the dimensions (data not shown).

#### Convergent validity

The Swedish RCAC total scale score and the Emotional Functional scale of the EORTC QLQ-C30 showed a negative correlation of moderate size (-0.361).

### Data quality

Descriptive statistics of the RCAC dimensions are presented in Table 1. Participants had the highest mean scores on the dimension Child's health 3.58 (SD 1.21) and the lowest mean scores on the dimension Partner disclosure 2.17 (SD 1.12). A floor effect above the customary cut-off of 15% was observed in the dimensions Fertility potential (21%), Partner disclosure (34.3%) and Becoming pregnant (17.1%). A ceiling effect (>15%) was detected in the dimension Child's health (17.7%).

## Reliability

The Cronbach's  $\alpha$  for four of the six dimensions was above the acceptable ( $\alpha > 0.70$ ), was questionable for the dimension Personal health ( $\alpha = 0.68$ ), and poor for the dimension Becoming pregnant ( $\alpha = 0.54$ ) [Table 1].

## Known-groups validity

The results for the known-groups validity investigation showed a significant difference in RCAC total mean scores between the three groups ( $F=29.54, p<0.001$ ). The differences in the mean scores was statistically significant between, on the one hand, women with a wish for (additional) children and, on the other hand, women who were uncertain if they wanted children (MD 3.41; 95% CI 1.68 to 5.14) and women who had no child wish (MD 4.56; 95% CI 3.13 to 5.99). No statistically significant difference in RCAC scores was observed between the latter two groups (uncertain vs no child wish) (MD 1.15; 95% CI -0.53 to 2.82).

## Discussion

In the present study, the psychometric properties of the Swedish RCAC scale were evaluated in young survivors of breast cancer while retaining the same factor structure as the original version of the scale. The translated and culturally adapted scale demonstrated face validity in evaluation with experts and persons from the target group. The CFA provided a satisfactory fit and all dimensions except Personal health and Becoming pregnant demonstrated acceptable reliability. Convergent validity of the Swedish RCAC was shown by a moderate correlation with emotional function and known-groups validity was demonstrated by statistically significant differences in RCAC scores between groups with and without a wish for (additional) children.

Our study has several methodological strengths. Firstly, the translation of the Swedish version of the RCAC scale was conducted based on the recommended two-panel approach (13). This was followed by its cultural adaptation including expert and lay panels. Another important strength of the design includes a nationwide population-based sample of young adult breast cancer survivors identified from a valid national quality register and thus minimised selection bias related to reproductive concerns.

The results for the absolute model fit index RMSEA suggested a reasonable error of approximation (16). The SRMR value was slightly outside the suggested range, but did not indicate a poor fit (16). The result of the relative model fit index CFI, indicated a reasonably good fit (16). It must be noted that fit indices may point to a well-fitting model when in actual fact, parts of the model may fit poorly (17). There are multiple guidelines available for "acceptable" model fit, but these are not rigid guidelines (22). In addition, it is of importance to consider the differences in life situation between the population used for the original scale development (9) and the present sample. Compared to women in the original sample, a higher proportion of women in the present sample had partners (87% vs 60%), had children (77% vs 17%) and a lower proportion of them had a wish for (additional) children (74% vs 36%) at the time of the survey. Moreover, the scale was developed based on a self-selected sample of female cancer survivors for whom reproductive concerns (mostly fertility potential) may have been a particularly relevant issue. The present population-based sample may be regarded as more representative of young adult breast cancer survivors, although a risk of selection bias cannot be ruled out. Considering these differences in sample selection and characteristics, the overall results of the model fit indices suggested a reasonable model fit of the data from the sample investigated in the present study. Convergent validity of the Swedish RCAC was indicated by a moderate correlation with emotional function, which is in line with previous reports of associations between reproductive concerns and emotional distress, depression and poor mental health (8, 23). As expected, and also observed in the original scale development sample (9), women who wanted to have children reported higher levels of reproductive concerns compared to those without a child wish.

Floor effects were observed among the dimensions Partner disclosure, Fertility potential and Becoming pregnant. A substantial proportion of the women in the present sample were in a partner relationship, already had children and had no wish for (additional) children. In young women with breast cancer, a greater concern about infertility is associated with a wish for children/more children and number of prior pregnancies (7). Hence it is not surprising that many participants chose the lowest possible scores in these dimensions. Similarly, a high ceiling effect was seen for the subscale Child's health, which focuses on concerns related to a potential hereditary risk of cancer for offspring. Again, considering that a majority of participants had children, it seems reasonable that a cancer experience may lead to worries regarding their child's health. Moreover, women who are diagnosed with breast cancer at a young age may experience greater psychosocial distress compared to older women (24), so it is likely that women being of younger age in our cohort have a greater reason to be concerned about genetic risk than other patient groups.

The results of the reliability measure of four of the six dimensions were above the acceptable range, in line with recent results for young female cancer survivors in the US (10). In our study the reliability for the subscale Personal health was nearly in the satisfactory range. The reliability of the subscale Becoming pregnant was poor in the current study. This subscale had the lowest Cronbach's alpha of the six subscales in the original study where the RCAC scale was developed (9) and again recently when analysed for psychometric properties (10). Although the Cronbach's  $\alpha$  for the Becoming pregnant dimension was below the acceptable range in our study, which was not the case in the other studies, it is noteworthy that the subscale performed similarly in two other populations with different demographics

(9, 10). The results suggest that it may be likely that this dimension is more difficult to comprehend than the other dimensions.

## Conclusions

The Swedish RCAC was found to have satisfactory factor structure and convergent validity, acceptable reliability in four of six dimensions and known-groups validity. The Swedish RCAC scale demonstrated suitable psychometric properties to be utilised in young adult female cancer survivors in Sweden.

## Abbreviations

ANOVA Analysis of variance

CFA Confirmatory Factor Analysis

CFI Comparative fit index

CI Confidence interval

EORTC QLQ-C30 European Organization for Research and Treatment of Cancer

MD Mean score differences

QLQ-C30 Quality of Life Questionnaire-C30

RCAC Reproductive Concerns After Cancer Scale

RMSEA Root mean square error of approximation

SRMR Standardized root mean residual

## Declarations

### *Ethics approval and consent to participate*

The ethical approval for the study was obtained from the Regional Ethical Review Board in Stockholm, Sweden (Ref No: 20131746-31/4). By responding to the survey, participants consented to participate in the study.

### *Consent for publication*

Not applicable.

### *Availability of data and materials*

The datasets generated and/or analysed during the current study are available from the principal investigators of the study on reasonable request.

### *Competing interests*

The authors declare that they have no competing interests.

### *Funding*

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### *Authors' contributions*

LW and CL conceived and planned the project and are principal investigators of the study. MW, LEE, LW and CL participated in study design, the translation/adaptation phase and data collection. All authors participated in the development of the analysis plan. PA and MW analysed the patient data and all authors contributed to the interpretation of the data. PA was a major contributor in writing the manuscript; all authors reviewed the manuscript for scientific content and approved the final manuscript.

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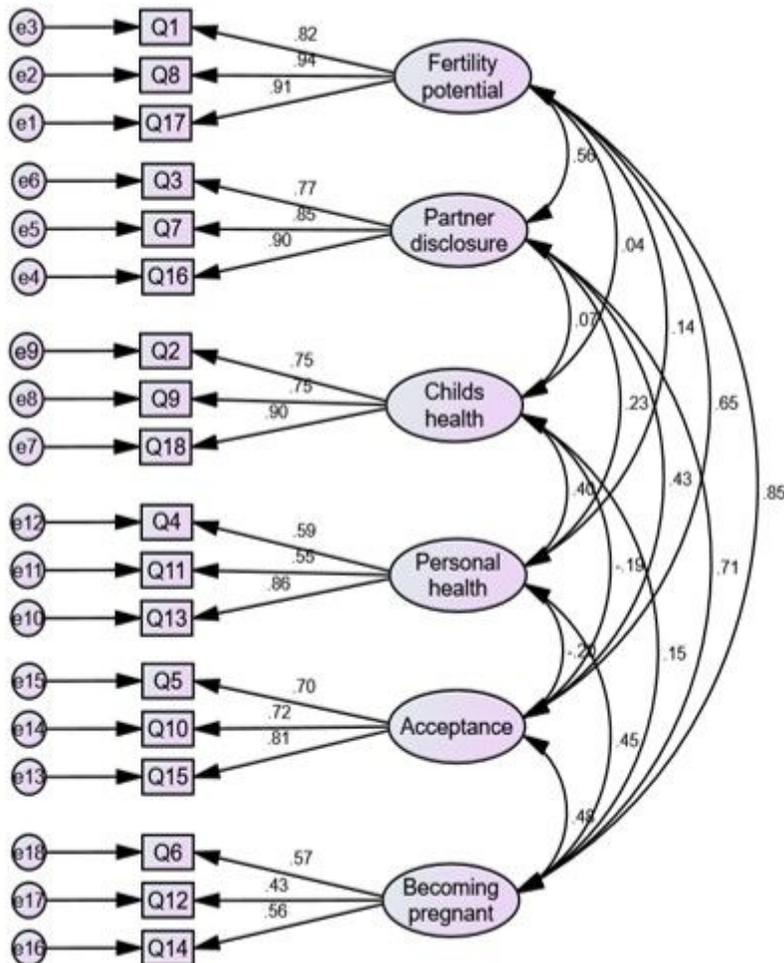
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## Tables

TABLE 1. Descriptive statistics and internal reliability of the six RCAC dimensions

Dimension	Mean	SD	Floor/ceiling effects (%)	Cronbach's $\alpha$
Fertility Potential	2.75	1.32	21/7.2	0.92
Partner disclosure	2.17	1.12	34.3/2.2	0.88
Child's health	3.58	1.21	6.1/17.7	0.84
Personal health	3.27	1.06	5.0/7.7	0.68
Acceptance	2.44	1.09	13.3/3.9	0.78
Becoming pregnant	2.41	0.90	17.1/2.2	0.54

## Figures



## Figure 1

Confirmatory Factor Analysis model of the Swedish RCAC scale on a sample of 177 breast cancer survivors