The European Portuguese version of the Reproductive Concerns After Cancer Scale (RCACS): A psychometric validation for young adult female cancer survivors

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Credit Author Statement

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The European Portuguese Version of the Reproductive Concerns After Cancer

Scale (RCACS): A psychometric validation for young adult female cancer

survivors

Abstract

Purpose: The purpose of this study was to evaluate the psychometric properties of the Portuguese version of the 18-item Reproductive Concerns After Cancer Scale (RCACS) among young adult female cancer survivors.

Methods: The psychometric validation was conducted based on a convenience sample of 192 cancer survivors aged between 18 to 40 years. An exploratory factor analysis (EFA) was used to test the factor structure of the Portuguese version of RCACS and reliabilities were examined. Convergent and discriminant validity was also used to assess the construct validity. The Hospital Anxiety and Depression Scale (HADS), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORT QLQ-C30) and the need for parenthood and rejection of child-free lifestyle subscales of the Fertility Problem Inventory (FPI) were used as convergent measures.

Results: A five-factor model was obtained with acceptable fit indexes and internal consistencies (.72<α<.89): (1) fertility potential, (2) children's health risk and future life, (3) partner disclosure, (4) barriers to getting pregnant/having children and (5) acceptance. Overall, convergent and discriminant validities were confirmed. Levels of anxiety and depression symptoms as well as health-related quality of life (QoL) had weak-to-moderate associations with reproductive concerns. Women who had a child or did not want a biological child were less concerned.

Conclusion: This scale proved to be a reliable and valid measure of reproductive concerns for the Portuguese population with potential relevance for application in clinical practice.

Keywords: motherhood, psycho-oncology, reproduction, women, younger.

Original Papers

The European Portuguese Version of the Reproductive Concerns After Cancer Scale (RCACS): A psychometric validation for young adult female cancer survivors

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1. Introduction

Anticancer treatments can cause fertility loss, threatening biological motherhood. In women under 40 years of age, exposition of the ovaries to alkylating chemotherapy or radiotherapy to the pelvis and abdomen or cranial and total body irradiation induce gonadotoxicity (Salama and Woodruff, 2017). More specifically, women with hormone receptor-positive breast cancer undergoing prolonged adjuvant hormonal therapy to reduce recurrence and mortality (Davies et al., 2013) have an increased risk of infertility with the induced aging of the reproductive system. This unwanted side effect can be distressing to the youngest survivors who have unfinished family building projects. Some of these women are faced with the fear of losing their motherhood dreams and their feminine identity (Assi et al., 2018).

Research has identified several concerns in women who have been diagnosed with cancer in reproductive age, which go beyond the ability to conceive. They report concerns related with a possible transmission of cancer risk to the child, malformations in the child, cancer recurrence after a potential pregnancy, complications during pregnancy (Sobota and Ozakinci, 2014), child-rearing responsibilities and future in the potential absence of the maternal figure (Coyne and Borbasi, 2008) and disclosure of infertility as a side effect of cancer in romantic relationships (Murphy et al., 2015). Consequently, these concerns seem to impair the psychosocial adjustment of young women (Benedict et al., 2018; Gorman et al., 2010; 2015) and, in some cases, lead to the refusal to initiate or discontinuation of cancer therapies (Llarena et al., 2015; Villarreal-Graza et al., 2017).

To our knowledge, in Portugal, there are no validated scales to assess the subjective perception of reproductive concerns after cancer among young adult female cancer survivors. However, epidemiological data estimated that there were approximately 96 new cases of cancer

per 100.000 Portuguese young adult females (20-39 years) in 2018, being the European country with the 12th highest incidence rate in this age range (Ferlay et al., 2019).

Despite international guidelines recommending fertility counseling for these young women (e.g. Oktay et al., 2018; National Comprehensive Cancer Network, 2019), barriers to discussing these issues with patients are still identified by Portuguese oncologists, namely related to lack of time, communication skills and patient-related characteristics (e.g. prognostic, status of marital relationship, high probability of fertility not being affected) (Melo, Fonseca, Silva, Almeida-Santos, & Canavarro, 2018). Thus, the needs of patients worried about their reproductive future may be neglected. For this reason, early identification of reproductive concerns through a reliable measure is a significant step towards being able to provide appropriate counseling and reducing the marginalization of patients in this country.

Overall, few scales identify the fertility and parenthood concerns of young women in reproductive age. Three measures have been most commonly used in the literature to assess reproductive concerns, these being the Reproductive Concerns Scale [RCS] (Wenzel et al., 2005), the Reproductive Concerns After Cancer Scale [RCACS] (Gorman et al., 2014; 2019) and items adapted from the Fertility Issues Survey (Partridge et al., 2004).

The Reproductive Concerns After Cancer Scale (RCACS) seems to be one of the most promising self-report instruments to evaluate these specific concerns, incorporating multiple dimensions such as fertility, pregnancy, children's health, disclosure and acceptance. This scale was originally developed in English (Gorman et al., 2014) and has been translated and adapted to Mandarin (Qiao et al., 2016) and Swedish (Ljungman et al., 2018). The validation studies of the English and Chinese versions including large samples of young women diagnosed with cancer

for at least one year showed strong psychometric qualities (Gorman et al., 2014; Qiao et al., 2016).

Therefore, the aim of this study was to evaluate the psychometric properties of the European Portuguese version of the RCACS among young adult females. The factor structure and internal consistency of this version were explored considering cultural differences. Furthermore, the relationship between the RCACS and theoretically related constructs was examined to determine the convergent validity of the measure, and discriminant validity was also investigated.

2. Methods

2.1. Participants

Young female cancer survivors aged between 18 and 40 who had been diagnosed at least one year prior to participation in the study, without a cognitive and physical inability to independently reply to the self-report measures, were eligible. Cancer survivors were excluded if they were currently pregnant or did not read and understand European Portuguese. Following these criteria, a total of 192 participants were recruited.

2.2. Procedure

Paper-and-pencil questionnaires and interviewing was the main data-collection method adopted in this study. A convenience sample of young women was recruited from the Gynecology and Obstetrics Department of Centro Hospitalar de São João, Porto, the Breast Clinic of Instituto Português de Oncologia Francisco Gentil in Porto and the Gynecology Department of the

Instituto Português de Oncologia Francisco Gentil in Coimbra, between October 2017 and July 2018. This study has been carried out in accordance with Declaration of Helsinki and informed consent was obtained from all participants. The entire protocol was also available via the online server of the University of Aveiro to increase the sample size since there is extensive evidence that the two forms of collection are equivalent (Gwaltney et al., 2008). The link to the survey was disseminated through newsletters, mailing lists and social networks. Of the 192 young women included, 144 participants completed the paper version of the questionnaire and 48 participants completed the online questionnaire.

2.3. Instruments

2.3.1. Socio-demographic and clinical questionnaire

A questionnaire assessing sociodemographic and clinical variables was administered. The patient's age, marital status, level of education and employment status were assessed. Participants' medical situation questions included variables such as cancer type, age at diagnosis, disease duration and previous treatments. Their reproductive history was also assessed, including the number of children, the desire to have more children, previous miscarriage and previous fertility care.

2.3.2. 18-item Reproductive Concerns After Cancer Scale (RCACS)

The RCACS is a self-report measure that contains 18 items assessing the fertility and parenthood concerns of young adult female cancer survivors. The original version of this scale (Gorman et al., 2014) measures six dimensions of reproductive concerns: fertility potential, partner disclosure, child's health, personal health, acceptance and becoming pregnant. For each item,

participants are asked to indicate their level of agreement with each statement using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). A mean score can be calculated for each dimension and total scores range from 18 to 90 points, with higher scores representing a higher level of concern. The English version of the RCACS has shown good reliability among samples of female survivors who were 18 to 35 years [alpha coefficient, $.78 \le \alpha \le .91$] (Gorman et al., 2014) and younger than age 45 [omega coefficient, $.66 \le \Omega \le .87$] (Gorman et al., 2019). The process of translation into European Portuguese was coordinated by the Quality of Life Office at the International Breast Cancer Study Group (IBCSG) involving the forward (English - Portuguese) and backward (Portuguese – English) technique and proof reading by three different translation agencies (see Figure 1). The final version was pre-tested with five breast cancer patients at the Cancer Center in Lisbon (Fundação D. Anna Sommer Champalimaud & Dr. Carlos Montez Champalimaud Centro de Investigação da Fundação Champalimaud). The version provided by the IBCSG was used in a previous study (Pagani et al., 2019). In the present study, we examined its psychometric properties.

2.3.3. Comparative measures

The 14-item Hospital Anxiety and Depression Scale (HADS) was used to assess the severity of anxiety and depression symptoms among cancer survivors [Portuguese version by Pais-Ribeiro et al. (2007)]. It is composed of two subscales including seven items evaluating anxiety (HADS-A) and seven items evaluating depression (HADS-D). Participants respond using a 4-point Likert scale and each domain obtains a total score ranging from 0 to 21. Higher scores indicate a higher level of anxiety or depressive symptoms. We found good reliability in this sample ($\alpha_{HADS-A} = .88$, $\alpha_{HADS-D} = .85$).

The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) [validated by Pais-Ribeiro et al. (2008)] is a thirty-item tool developed to assess health-related quality of life (QoL). This scale includes five functional scales, a global health status/QoL scale, three symptom scales and single-item measures. Participants are invited to respond using a 4-point Likert scale ranging from "not at all" to "very much". In this study, we only used the functional scales assessing physical, role, emotional, cognitive and social functioning and global health status/QoL scale. The scores for each subscale range from 0 to 100, with higher scores indicating better functioning of young adult female cancer survivors. Alpha coefficients were good in this sample (.72≤α≤.92).

Two subscales of the Portuguese version of the Fertility Problem Inventory (FPI; Moura-Ramos et al., 2012), associated with representations of the importance of parenthood, were also used as comparative measures. The need for parenthood subscale assesses the perception of parenthood as a main goal in life. In turn, the rejection of a child-free lifestyle subscale assesses the negative view of life without a child and how happiness can depend on it (Moura-Ramos et al., 2012). Participants are asked to rate how much they agree/disagree with each statement on a 6-point Likert scale, ranging from "Strongly disagree" to "Strongly agree". Both subscales showed good reliability (α =82, α =.83) for the need for parenthood and child-free lifestyle subscales, respectively.

2.4. Statistical analysis

Statistical analysis was performed with Statistical Package for Social Sciences, version 24 (SPSS Inc., Chicago) and MPlus, version 6.12 (Muthén & Muthén, Los Angeles, USA). The

characteristics of the young adult female cancer survivors were analyzed using descriptive statistics. We used an exploratory factor analysis (EFA) based on cultural and language differences. Furthermore, only two studies confirmed the original factor structure of the RCACS (Gorman et al., 2019; Qiao et al., 2016) and the most recent study showed that the six-factor model did not fit well statistically (Gorman et al., 2019). Given the ordinal nature of the RCACS, an EFA using weighted least squares with the mean and variance adjustment (WLSMV) estimator was conducted through MPlus (DiStefano and Morgan, 2014). This EFA approach allowed us to test the fit of alternative factor models. Based on the structure observed in the studies of Gorman et al. (2014; 2019), the upper limit of the number of factors to be extracted was six. We used oblique rotation (Oblimin) allowing correlations between factors. The screeplot and the eigenvalues one were the criteria used to identify the maximum number of factors to retain. Items that loaded above .4 on one of the factors were considered. The chi-square test (χ^2) , the root mean square error of approximation (RMSEA) and the Comparative fit index (CFI) evaluated the model's fit. An acceptable-fit model via an EFA should present a non-significant χ², RMSEA≤.08 and CFI>.90 (Kline, 2005). According to Nunnally (1978), one rule of thumb regarding sample size to perform an EFA is that the subject to item ratio should be at least 10 to 1. Based on this, the achieved sample size was enough to ensure stability of a factor solution. The internal consistency of the RCACS total scale and its factors was calculated using the Cronbach alpha coefficient. Values between .70 and .95 were considered acceptable (Terwee et al., 2007). For all statistical tests, the alpha level was 5% (two-tailed).

2.4.1. Construct validity: Hypotheses

Convergent validity was evaluated by examining Spearman's rank correlations between the RCACS and other validated scales. Following the guidelines presented by Ratner (2009), the correlations were classified as weak (0-0.3), moderate (0.3-0.7) and strong (>0.7-1.0). Based on previous literature, it was hypothesized that there would be positive associations between the subjective perception of reproductive concerns and depression and anxiety symptoms (Cândido et al., 2016; Gorman et al., 2010; 2015) and a weak-to-moderate negative correlation between these specific concerns and QoL (Benedict et al., 2018). These constructs were represented by measures such as HADS and EORTC QLQ-C30. We also hypothesized that the need for parenthood and the rejection of a child-free lifestyle measured by FPI subscales were conceptually distinct constructs, but correlated positively with the reproductive concerns reported by young women. Mann-Whitney nonparametric tests were also performed to assess differences in RCACS scores across groups. The predictions to identify discriminant validity were based on previous research. Thus, we hypothesized that participants aged <35 years (Ruddy et al., 2014) and who had self-reported a greater desire to have (more) biological children (Ljungman et al., 2018; Ruddy et al., 2011, Villarreal-Garza et al., 2017) would have higher rates of reproductive concerns. Additionally, childless women would also have higher concerns related to partners (or potential partners) and the ability to conceive (Corney and Swinglehurst, 2014; Dryden et al., 2014). Based on the original validation study (Gorman et al., 2014), comparisons were made between young women married or living in cohabitation with those who were not, hypothesizing that the former would have lower mean scores in the global scale.

3. Results

3.1. Sample characteristics

Cancer survivors were 18 to 40 years-old and mean age was 35.92 years (SD=3.96). Most participants were married/cohabiting (70.3%), had a university degree (51.5%) and were employed (86.9%). The most frequently reported diagnosis was breast cancer (81.3%) and mean age at cancer diagnosis was 32.20 (SD=4.80) years. More than 80% of participants had received chemotherapy and 60.4% were still undergoing treatment, namely endocrine adjuvant therapy. At the time of participating, 30% of the young women were being followed by a psychologist or psychiatrist. Concerning their reproductive history, about 57.8% of the young women had one or more children. The majority (83.3%) had received information about implications of the oncological treatments on fertility and 17.2% had previously undergone fertility care, for example, oocyte cryopreservation and oophoropexy. Among young adult female cancer survivors, 12.5% had had a previous miscarriage and more than 50% of participants wanted to have a (or another) biological child. The socio-demographic and clinical characteristics are presented in Table 1.

[INSERT TABLE 1 AROUND HERE]

3.2. Factor validity

According to the scree-plot, a factor structure including a maximum of five factors was suggested. Examining the fit measures, the 5-factor solution, conceptually justified, presented an acceptable fit (RMSEA=.07, 90% CI [.05, .09]; CFI=.98). A significant χ^2 was found, but due to the large sample size this test may be misleading [$\chi^2(73)=143.82$, p<.001] (Ulman and Bentler, 2003). There were no items with negative residual variance. The factor-item loadings ranged

from .511 to .970. The original six-factor model was not found, but two dimensions were replicated in our data, namely *partner disclosure of fertility status* (factor 3, 3 items; M=2.25; SD=1.13) and *acceptance* (factor 5, 3 items; M=2.49; SD=.98). Factor 1 observed in the new structure involved four items assessing concerns related to the ability/desire to have (more) children and getting pregnant (M=2.79, SD=1.13). Factor 2 included items related to children's health risk and future life (4 items; M=3.97; SD=1.07). Factor 4 contained four items relating to concerns about implications/barriers to getting pregnant or having children for one's own health and future (4 items; M=2.86, SD=.98). Table 2 presents mean scores for each item and factor loadings.

[INSERT TABLE 2 AROUND HERE]

3.3. Internal consistency

The total scale presented a Cronbach alpha coefficient of .84, indicating good internal consistency of the measure. Most of the item-to-total scale correlations were above .40. Even when we delete an item the alpha coefficient remained good (>.80) (see Table 2). Cronbach alpha coefficients for each of the five factors were acceptable, ranging from .72 to .89.

3.4. Convergent validity

As expected, the RCACS total scores were positively associated with anxiety and depressive symptoms and negatively associated with QoL sub-dimensions, except for role functioning. The need for parenthood was the variable most strongly associated with the RCACS index and, more

specifically, with dimensions such as fertility potential, partner disclosure and acceptance. Lower acceptance of the fertility status was moderately correlated with higher scores in the rejection of a child-free lifestyle subscale. The children's health risk and future life domain presented weak-to-moderate correlations with all the other scales. Higher concerns related to the barriers to getting pregnant/having children were more strongly associated with higher anxiety symptoms, but were not associated with representations about the importance of parenthood (see Table 3).

[INSERT TABLE 3 AROUND HERE]

3.5. Discriminant validity

Overall, participants who had not yet had children or who wanted to have a (another) biological child presented significantly higher RCACS total scores, compared to their counterparts who did not want (more) children. Concerning the domains of this scale, differences in scores across groups considering sociodemographic characteristics were also found. Women under the age of 35 had significantly higher mean levels of concerns related with fertility potential and lower acceptance compared to older women. We observed lower scores in the partner disclosure dimension for young women who were married or lived in cohabitation than for those who were not. However, these women reported higher concerns with potential fertility and children's health risk and future life. As hypothesized, childless women presented higher scores in dimensions such as fertility potential, partner disclosure and acceptance of fertility status than women who already had children. Table 4 shows that discriminant validity was obtained.

[INSERT TABLE 4 AROUND HERE]



4. Discussion

In this study we performed the validation study of the European Portuguese version of the RCACS by allowing the availability of the measure to assess the reproductive concerns of young adult female cancer survivors in a multifactorial perspective.

Contrary to expectations, the EFA of the scale data did not reveal the six-factor model confirmed by the English and Chinese versions (Gorman et al., 2019; Qiao et al., 2016). All items remained, but a different structure consisting of only five factors was obtained: (i) fertility potential, (ii) children's health risk and future life, (iii) partner disclosure, (iv) barriers to getting pregnant/having children and (v) acceptance. The dimensions related with disclosure and acceptance of the fertility status were composed of the same items as the original framework. However, the personal health and becoming pregnant domains of the American English version were not replicated here (Gorman et al. 2014). The items included in those subscales loaded on three different factors. Item 6 loaded on the fertility potential dimension being also related with ability to conceive. Item 4 loaded on the children's health risk and future life dimension that goes beyond health issues to involve concerns about the future of children also reported in the literature (Coyne and Borbasi, 2008). Lastly, items 11, 12, 13 and 14 loaded on the independent factor. This factor grouped concerns about how getting pregnant / having children can be a trigger for cancer recurrence, anxiety and routine changes. Based on these results, concerns related with barriers to motherhood showed to aggregate into a single dimension of the measure.

The acceptable fit indexes and loadings (>.50) show that all items measuring the factors support the five-factor model. The meaning and interpretation of the RCACS items are relevant aspects for the construction of the measure. There may have been some nuances in the participants' interpretation and response due to cultural and language differences that explain the

new factorial structure found in our data. Overall, young adult women included in this validation study showed similarities in terms of sociodemographic characteristics compared to samples used in other studies that confirmed the original factor structure. Nevertheless, breast and gynecologic cancers accounted for the majority of cases differing from the recent study by Gorman et al. (2019) involving mostly women diagnosed with breast cancer and lymphoma. The mean time since diagnosed cancer was four years. In turn, the Chinese version (Qiao et al., 2016) validation study included a sample, on average, diagnosed no more than two years ago. These and other clinical features can also contribute to differences in the results. In this regard, future work should (re) examine the fit of the RCACS factorial model and its invariance considering the two alternative solutions.

Cronbach alpha coefficients between .72 and .89 for the domains obtained revealed that the Portuguese version presented good internal consistency among young adult female cancer survivors. The coefficient of .84 for the entire scale was similar to that reported for the English version (Gorman et al., 2014) and higher than the Mandarin one (Qiao et al., 2016).

Similar to the other versions of the RCACS, evidence of convergent validity was confirmed by correlations of this scale with theoretically related constructs such as anxiety and depressive symptoms (Cândido et al., 2016; Gorman et al., 2010; 2015), QoL (Benedict et al., 2018) and representations of the importance of parenthood, as hypothesized. Among them, the need for parenthood subscale involving items related to the desire to be a mother was the variable showing the strongest associations with recalled reproductive concerns. This finding is consistent with previous studies that identified the wish for children as a positive predictor of these concerns (Villarreal-Graza et al., 2017). We also highlight that the children's health risk and future life domain of the RCACS had significant correlations with all other external scales.

This result suggests that these specific concerns have an impact on the psychological adjustment and functionality of the participants, in line with the literature presenting the child's health concerns as a primary emotional barrier to biological motherhood (Gorman et al., 2012).

In terms of discriminant validity, our hypotheses were partially supported. Young women who had children and who did not wish to have biological children in the future had lower RCACS total scores than their counterparts who had not yet had children and who wanted to have a (another) child, confirming previous findings (Ljungman et al., 2018; Ruddy et al., 2011; 2014; Villarreal-Graza et al., 2017). Additionally, it was possible to distinguish specific concerns among women who wanted and did not want to have (other) children. Women who did not report a desire to have a (another) biological child were less worried about potential fertility and disclosure issues, but had similar scores regarding concerns related to children's health risk and future life and barriers to getting pregnant/having children. Also, according to our predictions, childless women presented higher concerns about their fertility status and disclosure to their partners. Research had suggested these women felt that uncertainty about their fertility made future planning difficult (Corney and Swinglehurst, 2014) and, in some cases, they report fear of rejection by partners (Dryden et al., 2014).

In turn, differences between the groups of married or cohabiting survivors and those who were not were replicated at the global scale level. However, women who were not married or in a committed relationship presented higher scores in the partner disclosure dimension. This is not surprising since the disclosure of cancer history and the potential loss of fertility can be particularly difficult for young women who do not yet have a marital relationship but imagine having a partner in the future or who have not yet made the decision to form a family as a couple. Living with the partner in same household can also allow their greater involvement

during the diagnosis and treatment process, minimizing the barriers to discussing the fertility status. Furthermore, younger women (< 35 years old) reported higher concerns related with fertility, as previously shown (Ruddy et al., 2014), and lower acceptance of the potential infertility status, but differences were not found for other subscales. Qualitative data had already shown that women in their 30s felt the time to start a family was running out, reporting pressure to find a partner and try to have a child (Corney and Swinglehurst, 2014).

Despite the encouraging findings, this study reveals limitations that should be noted. First, the homogeneity of the cancer type; the majority of the participants (81.3%) had breast cancer while the instrument has been developed for samples with diverse characteristics including different cancer Second, there assessment types. no reproducibility/repeatability as in the Chinese version (Qiao et al., 2016). Third, the infertility risk depends on multiple factors but differences in reproduction-related concerns according to cancer type, surgery type and therapies with high or lower risk could not be determined. Further studies should consider these characteristics to investigate discriminant validity, as suggested by Gorman et al. (2014). However, strengths should also be pointed out. This study involved participants from the north, south and center of Portugal, including women with and without the desire for biological motherhood.

5. Conclusion

This study contributes to a growing body of evidence about the psychometric properties of the RCACS, which has only been translated and validated for two countries. Our results suggest that the European Portuguese version of the RCACS scale seems to be a reliable and valid measure to assess the multiple dimensions of reproductive concerns among young adult

female cancer survivors. However, a new five-factor structure has been proposed, which may provide relevant implications for future research. A return to examining the dimensional structure of the RCACS is instigated. Furthermore, to our knowledge, this is the first validated measure to assess reproductive concerns in Portugal. Therefore, using this measure in clinical practice may contribute to reducing counseling inequalities by facilitating appropriate assessment and discussion of patient concerns. The RCACS is simple to administer and can be used in routine appointments to assess younger women.

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Declaration of interest

No potential conflict of interest was reported by the authors.

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Table 1. Socio-demographic and clinical characteristics of the young female cancer survivors (n=192).

| Characteristic | N | % | | |
|---|---------------------|-------------|--|--|
| Age in years (M±SD, range) | 35.92±3 | 3.96, 18-40 | | |
| Marital status | | | | |
| Married/cohabiting | 135 | 70.3 | | |
| Single | 42 | 21.9 | | |
| Divorced/separated | 15 | 7.8 | | |
| Education | | | | |
| Primary school | 3 | 1.6 | | |
| Middle school | 32 | 16.7 | | |
| High school | 58 | 30.2 | | |
| University | 99 | 51.5 | | |
| Employment status | | | | |
| Employed/Self-employed | 167 | 86.9 | | |
| Unemployed | 16 | 8.3 | | |
| Student | 4 | 2.1 | | |
| Disability pension | 4 | 2.1 | | |
| Number of children | | | | |
| No children | 81 | 42.2 | | |
| 1 child or more | 111 | 57.8 | | |
| Cancer type | | | | |
| Breast cancer | 156 | 81.3 | | |
| Cervical cancer | 6 | 3.1 | | |
| Ovarian cancer | 12 | 6.3 | | |
| Endometrial cancer | 1 | .5 | | |
| Leukemia | 4 | 2.1 | | |
| Hodgkin lymphoma | 4 | 2.1 | | |
| Non-hodgkin lymphoma | 2 | 1.0 | | |
| Thyroid | 4 | 2.1 | | |
| Sarcoma | 3 | 1.5 | | |
| Time since initial diagnosis in months | 45.50±30.75, 12-180 | | | |
| (M±SD, range) Age at diagnosis in years (M±SD, range) | 32.20±4.80, 9-40 | | | |

| Cancer treatment | | _ |
|--|-----|------|
| Chemotherapy | 159 | 82.8 |
| Radiotherapy | 135 | 70.3 |
| Current stage of the cancer treatment | | |
| Undergoing treatment | 116 | 60.4 |
| Follow-up | 75 | 39.1 |
| Use of mental health services | | |
| Yes | 30 | 15.6 |
| No | 162 | 84.4 |
| Previous miscarriage | | |
| Yes | 24 | 12.5 |
| No | 166 | 86.5 |
| Information about fertility-related implications | .0 | |
| Yes | 160 | 83.3 |
| No | 32 | 16.7 |
| Previous fertility care | | |
| Yes | 33 | 17.2 |
| No | 156 | 81.3 |
| Wants a (or another) biological child | | |
| Yes | 99 | 51.6 |
| No | 86 | 44.8 |

Table 2. Items' mean scores, factor loadings and reliability of the identified factors of the RCACS.

| | | Fertility potential | Children's health risk and future life | Partner Disclosure | Barriers to getting pregnant/ having children | Acceptance |
|------|---------------|------------------------|--|-----------------------|---|-------------------|
| Item | M±SD | Factor 1 | Factor 2 | Factor 3 | Factor 4 | Factor 5 |
| No. | MESD | (a=.873) | $(\alpha = .857)$ | (a=.888) | $(\alpha = .732)$ | $(\alpha = .718)$ |
| 1 | 3.19±1.40 | .847 | .066 | .009 | .014 | 132 |
| 2 | 3.81±1.36 | .075 | .850 | 006 | 077 | 098 |
| 3 | 2.39±1.30 | .078 | .003 | .773 | .086 | .008 |
| 4 | 4.23±1.11 | .024 | .695 | 125 | .261 | 118 |
| 5 | 2.37±1.18 | 010 | .019 | .008 | 024 | .727 |
| 6 | 2.42±1.26 | .647 | 023 | .087 | .040 | .149 |
| 7 | 2.22±1.26 | .104 | .028 | .845 | 062 | 088 |
| 8 | 2.69 ± 1.33 | .893 | 067 | 014 | .039 | .086 |
| 9 | 3.81±1.34 | 074 | .869 | .122 | .051 | .205 |
| 10 | 2.24 ± 1.20 | .094 | 011 | .042 | 018 | .569 |
| 11 | 3.04 ± 1.38 | .014 | .076 | .088 | .649 | 155 |
| 12 | 2.72±1.32 | 088 | 093 | .145 | .676 | 036 |
| 13 | 3.08±1.36 | .088 | .292 | 098 | .629 | 055 |
| 14 | 2.54±1.21 | .198 | 101 | .080 | .618 | .166 |

| 15 | 2.87±1.30 | .280 | .145 | .028 | 108 | .511 |
|----|---------------|------|------|------|------|------|
| 16 | 2.13±1.19 | 043 | .019 | .970 | .037 | .049 |
| 17 | 2.84 ± 1.35 | .806 | 016 | .122 | 028 | .024 |
| 18 | 4.02 ± 1.27 | 038 | .918 | .003 | 041 | 007 |

Journal Pre-location

Table 3. Convergent validity: correlations between subjective perception of reproductive concerns (RCACS) and distress (HADS-D and HADS-A), Quality of Life sub-dimensions and representations about the importance of parenthood.

| Factor | HADS-D | HADS-A | PF | RF | EF | CF | SF | Global health status/QoL | Need for parenthood | Rejection of child-free lifestyle |
|--|---------|---------|--------|-------|--------|--------|--------|--------------------------------|---------------------|-----------------------------------|
| Fertility potential | .089 | .033 | .037 | 070 | 064 | 078 | 040 | .090 | .411*** | .192** |
| Children's health risk and future life | .287*** | .352*** | 358*** | 219** | 292*** | 272*** | 319*** | .235** | .266*** | .283*** |
| Partner Disclosure | .153* | .125 | 001 | .056 | 066 | 005 | 070 | .037 | .301*** | .207** |
| Barriers to getting pregnant/ having children | .191** | .289*** | 199** | 092 | 201** | 081 | 227** | .087 | 017 | 002 |
| Acceptance | .257*** | .176* | 024 | 088 | 129 | 161* | 092 | .138 | .453*** | .347*** |
| RCACS total score | .255*** | .280*** | 162** | 121 | 229** | 158* | 241*** | .187* | .416*** | .265*** |

Note: HADS-D = Depression; HADS-A = Anxiety; PF = Physical functioning; RF= Role functioning; EF= Emotional functioning; CF= Cognitive functioning; SF= Social functioning; *** p<.001; **p<.01; * p<.05.

Table 4. Discriminant validity: differences in RCACS scores across groups using the Mann-Whitney test.

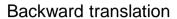
| | Fertility potential | | Children's health risk and future life | | Partner Disclosure | | Barriers to getting pregnant/ having children | | Acceptance | | | RCACS total score | | | | | | |
|-------------------------------|---------------------|------|---|------|--------------------|-----------|---|------|------------|------|------|-------------------|------|------|-----------|-------|-------|------------------|
| | M | SD | Statistic | M | SD | Statistic | M | SD | Statistic | M | SD | Statistic | M | SD | Statistic | M | SD | Statistic |
| Age | | | | | | | | | | | C | | | | | | | |
| <35 years | 3.13 | 1.04 | 2743** | 3.86 | 1.03 | 3335 | 2.48 | 1.21 | | 2.75 | 1.04 | 2 . 3392 | 2.73 | 1.07 | 2829*** | 55.33 | 11.39 | 2831.5 |
| ≥35 years | 2.65 | 1.15 | 2743 | 4.01 | 1.08 | 3333 | 2.15 | 1.08 | 3209 | 2.88 | .96 | 3392 | 2.40 | .93 | 2029 | 51.69 | 11.97 | |
| Married/ cohabiting | | | | | | | | | | 3 | | | | | | | | |
| Yes | 2.73 | 1.12 | 3367.5 | 4.09 | 1.03 | 3008.5* | 2.01 | .99 | 2461.5** | 2.86 | 1.01 | 3627.5 | 2.44 | .95 | 3209.5 | 52.04 | 13.30 | 3044 |
| No | 2.92 | 1.16 | 3307.3 | 3.69 | 1.12 | 3008.3 | 2.80 | 1.24 | * | 2.82 | .93 | | 2.62 | 1.05 | 3209.3 | 54.37 | 13.30 | 30 11 |
| Already having children | | | | | | | | 10, | | | | | | | | | | |
| Yes | 2.47 | 1.03 | 2739.5* | 4.27 | .87 | 2849*** | 1.93 | .85 | 3088.5** | 2.84 | 1.01 | 4210 | 2.35 | .90 | 2242* | 51.13 | 10.05 | 2207.5* |
| No | 3.21 | 1.14 | ** | 3.56 | 1.17 | 2849*** | 2.67 | 1.32 | * | 2.86 | .95 | 4310 | 2.69 | 1.06 | 3342* | 54.91 | 13.78 | 3297.5* |
| Desire to have children | | | | | | | | | | | | | | | | | | |
| Yes | 3.36 | .93 | 1453*** | 4.05 | .96 | 4126 | 2.53 | 1.15 | 2881.5** | 2.91 | .91 | 3694.5 | 2.77 | .91 | 2414*** | 57.30 | 10.24 | 1852.5* |
| No | 2.10 | .94 | 1733 | 3.91 | 1.15 | 7120 | 1.91 | .98 | * | 2.74 | 1.05 | 3094.3 | 2.18 | .99 | Z414*** | 47.08 | 10.57 | ** |

Note: M=Mean; SD=Standard deviation; *** p<.001; **p<.001; * p<.05.

Figure Legend:

Figure 1. An overview of the phases and steps of cross-cultural adaptation and validation of the European Portuguese version of the Reproductive Concerns After Cancer Scale (RCACS).

Forward translation



Proof reading

Pretesting (N=5)

Final version

Administration (N=192)

Extraction of factors

Internal consistency

Convergent/discriminant validity

This phase was coordinated by the Quality of Life Office at the International **Breast Cancer** Study Group (IBCSG)

This phase has been carried out in the present study

Highlights

- Evidence suggest that young women diagnosed with cancer report reproductionrelated concerns.
- The Reproductive Concerns After Cancer Scale (RCACS) is a reliable and valid self-report measure.
- Results from the Portuguese version of RCACS demonstrated a five-factor structure.
- An early identification of concerns may reduce the marginalization of patients.

Conflict of Interest Statement

No potential conflict of interest was reported by the authors.