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Assessing Fear of Cancer Recurrence among Adolescents and Young Adults: The Portuguese Validation and Psychometric Assessment of the "Fear of Cancer Recurrence 7" Scale

Avaliar o Medo de Recorrência do Cancro em Adolescentes e Jovens Adultos: A Validação Portuguesa e Avaliação Psicométrica da Escala "Medo de Recorrência do Cancro 7"

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ABSTRACT

Introduction: Adolescents and young adults with cancer experience high levels of fear of cancer recurrence (FCR), negatively impacting their lives. However, no measure has been validated worldwide to assess FCR levels among these young people. This study aims to validate the FCR7, a scale that measures FCR, for the Portuguese population of adolescents and young adults.

Methods: Ninety-two participants were recruited online. They were primarily women (83.7%) with a mean age of 26.01 years at recruitment and 19.38 years at cancer diagnosis, with a variety of cancer diagnoses and previous treatments. Most participants were no longer under active treatment (75%), and approximately 75.1 months had passed since their diagnosis. Fear of cancer recurrence, anxiety and depression levels, and quality of life were assessed.

Results: The results showed that FCR7 has good model fit and reliability. Concurrent and divergent validity were also confirmed, with FCR being positively related to anxiety and negatively associated with quality of life. A cut-off score was found, discriminating between clinical and non-clinical levels of FCR. Almost 70% of the participants experienced clinical levels of FCR. We conclude that FCR7 is a valid unidimensional scale to assess FCR levels among Portuguese adolescents and young adults.

Conclusion: More research should be conducted to validate FCR measures to be used among adolescents and young adults across the globe. The existence of a valid and brief measure to assess FCR among this population in Portugal is an asset for national health professionals and researchers.

Keywords: Adolescent; Fear/psychology; Neoplasm Recurrence, Local/psychology; Psychometrics; Reproducibility of Results; Surveys and Questionnaires; Young Adult

RESUMO

Introdução: Os adolescentes e jovens adultos com cancro experienciam níveis elevados de medo da recorrência do cancro (FCR), podendo ter um impacto negativo nas suas vidas. Contudo, ainda nenhuma medida foi validada para avaliar os níveis de FCR nestes jovens a nível mundial. Este estudo tem como objetivo validar a FCR7, uma escala que mede o FCR, para a população portuguesa de adolescentes e jovens adultos.

Métodos: Noventa e dois participantes foram recrutados *online*. Eram maioritariamente mulheres (83,7%), com uma idade média de 26,01 anos no momento do recrutamento e de 19,38 anos no momento do diagnóstico de cancro, com uma variedade de diagnósticos de cancro e tratamentos anteriores. A maioria dos participantes já não se encontrava em tratamento ativo (75%) e tinham passado aproximadamente 75,1 meses desde o diagnóstico. Os níveis de FCR, ansiedade e depressão e qualidade de vida foram avaliados.

Resultados: Os resultados mostraram que a escala FCR7 tem um bom ajuste e fiabilidade. As validades concorrentes e divergentes foram também confirmadas, com o FCR correlacionando-se positivamente com a ansiedade e negativamente com a qualidade de vida. Um ponto de corte foi identificado, permitindo discriminar entre níveis clínicos e não clínicos de FCR. Quase 70% dos participantes apresentaram níveis clínicos de FCR.

Conclusões: Conclui-se que a FCR7 é uma escala unidimensional válida para avaliar os níveis de FCR nos adolescentes e jovens adultos portugueses. É importante haver mais investigação para validar medidas de FCR para esta população mundialmente. A existência de uma medida válida e breve para avaliar o FCR entre os adolescentes e jovens adultos em Portugal é uma mais-valia tanto para os profissionais de saúde, como para os investigadores nacionais.

Palavras-chave: Adolescente; Adulto Jovem; Inquéritos e Questionários; Medo/psicologia; Psicometria; Recidiva Local de Neoplasia/psicologia; Reprodutibilidade dos Resultados

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KEY MESSAGES

- This is the first study worldwide to validate a measure to assess fear of cancer recurrence (FCR) among adolescents and young adults (AYAs).
- Fear of Cancer Recurrence 7 is a valid and reliable self-report measure to assess FCR levels in Portuguese AYAs.
- The scale allows the identification of AYAs with clinical levels of FCR who may need additional support.
- The FCR7 validation to Portuguese AYAs is an asset to national healthcare professionals and researchers.
- More measures need to be developed and/or validated with the unique needs and characteristics of AYAs in consideration.

INTRODUCTION

After being diagnosed with cancer, some people experience concerns that the disease may progress. Similarly, some of those who are in remission may worry about the cancer returning. This "fear, worry, or concern about cancer returning or progressing" is known as fear of cancer recurrence (FCR).[1] This is a normal response after diagnosis, as there is a real possibility that the cancer might return or progress. This fear is also a complex and intense experience, frequently present in patients' lives[2] with significant impact, making it one of their top concerns.[2,3]

The Self-Regulation Model of Illness by Lee-Jones *et al*[4] was the first model to try to understand FCR. It looked at FCR from a cognitive behavioral perspective and hypothesized that it varies according to each person's illness representation. The authors suggested that internal and external cues are antecedents that can activate cognitions, beliefs, and emotions related to FCR, depending on how they are interpreted. This can lead to behavioral and psychological consequences, which can further influence the cognition and interpretation related to them. Some examples of these triggers have been found in the literature, like bodily sensations, waiting for medical tests or appointments, and hearing, talking, reading, thinking, or remembering things about cancer or their experience.[2,5] Some FCR experts also pointed out that persistently high levels of preoccupation and/or worry and hypervigilance about physical symptoms of a possible recurrence are key features of clinical FCR.[6] These findings seem to support the role that internal and external cues play in the experience of FCR, but more evidence is needed.

Even though most sociodemographic and clinical characteristics have not been associated with high FCR in a systematic review of adults with cancer,[3] younger age has been frequently related to high levels of FCR.[3,7,8] This association was found in systematic reviews, some with meta-analysis, that focused on cancer patients over 18 years of age, suggesting that younger cancer patients can be at an elevated risk for experiencing higher FCR levels than older cancer patients.

Studies with adolescents and young adults (AYA) diagnosed with cancer between the ages of 15 and 39[9] have found that 13% - 62% of patients report high levels of FCR.[10] This prevalence is higher than what has been found for older adults.[3,8] Most of the evidence on FCR among AYAs was synthesized by Yang *et al*[10] in their systematic review. They found that those with higher FCR levels experienced higher distress and anxiety levels and lower quality of life. Additionally, a negative association was found between FCR and quality of life, as well as physical and psychological functioning. More recent papers had results in line with what had been previously found. They've found that anxiety and depression symptoms were positively related to FCR levels[11,12] and that experiencing psychological distress, posttraumatic symptoms, and anxiety predicts high FCR levels.[13] These findings are similar to what has been previously found in the literature with adults.[3] Regarding its trajectory over the years, it has been found that for approximately one-third of young breast cancer survivors, FCR levels can worsen or stay high for up to five years post-diagnosis.[14] Considering the high prevalence of FCR among AYAs, its significant impact on their mental health, and the fact that, for many survivors, it can remain high or even worsen over the years, it is important to further address this topic.[10-13]

Adolescents and young adults have an extensive age range encompassing subgroups that differ regarding their physiological and psychological development.[15] As in previous studies,[16] this study focused exclusively on younger AYAs, aged 15 to 25 years at diagnosis. This approach ensures that the included participants were sufficiently homogeneous, with more similar development challenges.

The evidence shows that the number of children, adolescents, and young adult cancer survivors is increasing in Europe every year and is expected to continue increasing.[17] In Portugal, 52 723 people were diagnosed with cancer in 2020, with 2045 of these occurring in young people between the age of 15 and 39. Of these new diagnoses, 330 happened in patients between 15 and 24 years old, with roughly the same incidence in male (n = 177) and female (n = 153) individuals.[18] Even though they correspond to a small portion of all cancer diagnoses in Portugal, the incidence has increased in the last 20 years.[19] Adolescents and young adults have specific characteristics and needs

that distinguish them from children and adults. One of these differences is their greater cognitive capacity, which allows them to better understand the severity of their diagnosis compared to children.[20] This makes AYAs a unique cancer group that is still underrepresented in cancer research, including in Portugal.

Among all the studies investigating FCR in AYAs, measures used to assess FCR were not previously validated for this population. In the systematic review by Yang *at al*,[10] they found instruments like the Cancer Worry Scale, Concerns About Recurrence Scale, and the short form of the Fear of Progression Questionnaire were the most frequently used instruments. Additionally, some studies also used a single question to assess FCR, and others used study-specific questions. The most recent papers on FCR in AYAs kept using measures like the short-form versions of the Fear of Progression Questionnaire[11,21] and the Fear of Cancer Recurrence Inventory,[12,13] which are only validated for adults. There are no guarantees that measures validated for adults will be valid or suited for younger populations, like AYAs. Thus, such measures must be validated for the AYA population.[10,22] Validating a measure to assess FCR levels for AYAs would ensure that the measure used is really suitable for this population. This could improve research and provide healthcare professionals with a valid tool for assessing FCR levels in AYA.

One concern with the aforementioned measures is that they were developed before the accepted definition of FCR was developed. Some are also extensive, making them time-consuming and burdensome when added to a study protocol or in clinical practice. It has been suggested that an instrument with few items could be the best way to assess FCR.[23] One instrument that checks these criteria is the recently developed FCR7 scale.[24]

Published in 2018, the FCR7 is a short unidimensional measure with only seven items that can be used as a screening instrument. When needed, it can be followed by a more extensive assessment, with other questionnaires or a clinical interview. The psychometric properties of FCR7 have been studied in detail, supporting its use in adults. This scale is widely used and, as far as we know, was validated for China,[25] India,[26] and Brazil.[27] In this latest validation, 41.3% of participants preferred FCR7 over another frequently used FCR scale.[27] Table 1 shows the psychometric properties of the original and translated version of FCR7 in more detail.

At the time this study was carried out, no measure for FCR had been validated for Portugal or AYAs. Considering that FCR7 is a short, simple, and valid widely used measure of FCR, validation for Portuguese AYAs seems like a good initiative. Therefore, the aim of this was to validate the FCR7 for the Portuguese population of AYAs. In addition,

Table 1 – Psychometric characteristics of published validations of FCR7

Author, year	Country	Sample	Number of items	Number of dimensions	Modification index adjustments	Internal consistency	Concurrent validity	Divergent validity
Humphris *et al*, 2018[27]	Scotland	206 breast cancer patients and 53 colorectal	7	1	Not reported	α = 0.92	Variable: anxiety Measure: HADS* If obtained: Yes	Variable: depression Measure: HADS* If obtained: Yes
Lee *et al*, 2020[28]	China	160 early-stage lung cancer patients	7	Unidimensional	Item 4 - Item 5; Item 5 - Item 6	α = 0.9	Variable: anxiety Measure: HADS* If obtained: Yes	Variable: quality of life Measure: EORTC QLQ-C30** If obtained: Yes
Nandakumar *et al*, 2022[29]	India	106 breast cancer survivors	7	Not assessed	Not applicable	α = 0.86	Not clear***	Not clear***
Bergerot *et al*, 2023[30]	Brazil	100 with localized cancer and 100 with metastatic cancer	7	Unidimensional	Item 1 - Item 2; Item 1 - Item 7	α = 0.89	Not assessed	Not assessed

* HADS: Hospital Anxiety and Depression Scale;
** European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30;
*** Authors performed correlation analysis but did not state clearly if or which were to assess convergent and divergent validity.

the study also intends to use patient and public involvement (PPI) to improve the study materials.

METHODS

Participants

A sample of Portuguese AYAs with cancer was recruited online. To be eligible for this study, participants had to (a) have had a previous cancer diagnosis and (b) have been between the ages of 15 and 25 at diagnosis. No limits were imposed on time after diagnosis and survivorship phase since the evidence shows no association between most clinical variables and FCR levels.[3,10]

One hundred twenty-one participants were initially recruited. Of these, 26 did not have a cancer diagnosis between the ages of 15 and 25, one was not a cancer patient, and two other participants were found to be extreme outliers in terms of age and time since diagnosis. Thus, the final sample included 92 participants. These were mostly women (83.7%), single (82.6%), and employed full-time (46.7%) or students (33.7%). Participants were between 15 and 47 years old at recruitment and 15 and 25 at diagnosis. Most were diagnosed up to five years (60 months) prior to their participation, with a wide variety of cancer diagnoses and previous treatments. Most were no longer under active treatment (75%), and only 16.3% had a recurrence. More details about the participants' sociodemographic and clinical characteristics can be found in Table 2.

Measures

A sociodemographic and clinical questionnaire was included. This questionnaire assessed the participant's age at recruitment, sex, marital status, education, and professional situation. As for medical information, it included age at cancer diagnosis, type of cancer diagnosis, time since diagnosis, treatment phase at recruitment, previous treatments, previous recurrences, and whether they had needed psychological support.

The FCR7 scale[24] assessed FCR levels. This scale was already translated and culturally adapted to Portuguese by another research team and is currently being validated for adult cancer survivors in Portugal. However, this version has not been published yet. The FCR7 is a unidimensional scale that includes six items on a five-point Likert scale and one item, the last one, scored on an 11-point scale. One example of an item is "I am afraid that my cancer may recur". In the original article, an excellent internal consistency was found (α = 0.92). A higher score indicates a higher FCR.

Additionally, we used the Hospital Anxiety and Depression Scale[28,29] to assess anxiety and depressive symptoms. This measure includes 14 items on a four-point Likert scale. Higher scores indicate higher levels of anxiety and depressive symptoms. These symptoms can be classified as normal (0 - 7), mild (8 - 10), moderate (11 - 14), and severe (15 - 21). One example of the anxiety subscale is "I get a sort of frightened feeling as if something awful is about to happen". At the same time, "I still enjoy the things I used to enjoy" exemplifies the type of items in the depression subscale. The Portuguese version showed good internal consistency for both anxiety (α = 0.76) and depression (α = 0.81) subscales. In this study, Cronbach's alpha of 0.87 and 0.77 were found for anxiety and depression, respectively.

Finally, the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30[30,31] was used to assess the quality of life of cancer patients. It includes 30 items on a four-point Likert scale. An example of an item is "Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?". A higher score implies better functioning, except for symptom subscales, where higher scores point to higher symptoms. The Portuguese version showed good internal consistency, ranging from 0.74 to 0.88, except for the subscale of cognitive functioning, which showed an internal consistency of 0.52. In our sample, it ranged from 0.79 to 0.88, apart from the cognitive functioning subscale with a 0.69 Cronbach's alpha.

Procedure

Patient and public involvement

Before starting the data collection for the validation study, patients and the public were involved in two pilot studies. The first pilot study included two young cancer survivors and two members of the Acreditar association. This Portuguese association focuses on young people with cancer and their families. One of the members of this association was also a cancer survivor, while the other had a psychology degree. We received feedback regarding our study materials and the questionnaire. One of the young people with cancer could not attend the feedback meeting. Some problems were raised about the wording of some items of the FCR7 scale, which needed to be made clearer. Considering this, a second pilot study was undertaken to adapt the items to AYAs. Seven young people with cancer between the ages of 15 and 25 collaborated with the team. They analyzed the items of the FCR7 scale and suggested clearer wording when necessary. After this, since the wording of some items had been slightly modified, the FCR7 scale was backward translated to English and sent to the author of the original scale.

Data collection

After the author's approval, recruitment for the validation study began. The platform InquéritoUP powered by LimeSurvey was used to create online questionnaires. The questionnaire was disseminated online by two Portuguese

Table 2 – Sociodemographic and clinical characteristics of the participants

	n	%	Range	Mean	Median	Quartile	SD
Sex							
Women	77	83.7%					
Men	15	16.3%					
Age at recruitment (years)			15 - 47	26.01	25.5	Q1 = 22 Q3 = 29	6.2
Marital status							
Single	76	82.6%					
Non-marital partnership	8	8.7%					
Married	8	8.7%					
Education level							
Middle school	6	6.5%					
High school	31	33.7%					
Bachelor's degree	33	35.9%					
Masters' degree	21	22.8%					
Doctorate degree	1	1.1%					
Occupational status							
Student	31	33.7%					
Full-time employee	43	46.7%					
Part-time employee	2	2.2%					
Unemployed	9	9.8%					
Other	7	7.6%					
Age at cancer diagnosis (years)			15 - 25	19.38	18.5	Q1 = 16 Q3 = 23	3.67
Time since diagnosis (months)			1 - 360	75.4	60	Q1 = 18.5 Q3 = 108	71.6
Up to 60 months	52	56.5%					
61 - 120 months	23	25.0%					
More than 120 months	17	18.5%					
Cancer diagnosis							
Leukemia	18	19.6%					
Hodgkins lymphoma	24	26.1%					
Non-Hodgkins lymphoma	4	4.3%					
Thyroid cancer	6	6.5%					
Sarcoma	11	7.6%					
Brain cancer	7	7.6%					
Breast cancer	7	7.6%					
Ovarian cancer	3	3.3%					
Other	12	17.4%					
Treatment status							
Active/Under treatment	23	25.0%					
No longer under treatment	69	75.0%					
Previous treatments							
Surgery	43	46.7%					
Radiotherapy	43	46.7%					
Chemotherapy	73	79.3%					
Hormonal therapy	4	4.3%					
Immunotherapy	4	4.3%					
Transplant	10	10.9%					
Other	5	5.5%					
Had a recurrence	15	16.3%					
Needed psychological support	43	46.7%					

associations focused on young people with cancer (Acreditar and Fundação Rui Osório de Castro) on their network and social media platforms. The questionnaire was also shared in Facebook groups and Instagram pages directed towards cancer patients and survivors. Recruitment occurred between November 25, 2022, and February 28, 2023.

This validation study was approved by the Ethics Committee of the Faculty of Psychology and Education Sciences of the University of Porto (Reference number: 2022/03-06c; Date of approval: July 13, 2022).

Data analysis

The data analysis was conducted using SPSS version 28 and MPlus version 22, with a significance level of p = 0.05 (two-tailed). Analyses included descriptive statistics, normality checks, correlations, and internal consistency to evaluate item properties. Internal consistency was assessed using Cronbach's alpha, with values between 0.70 and 0.95 deemed acceptable.[32] Confirmatory factor analysis (CFA) was performed to evaluate the construct validity of the Portuguese FCR7 for AYAs, aiming to confirm its unidimensionality and fit compared to the original[24] and translated versions.[25-27] Model fit was assessed using chi-square analysis (χ^2), root mean square error of approximation (RMSEA), comparative fit index (CFI), and weighted root mean square residual (WRMR).[33-35] Criteria for acceptable fit were χ^2 non-significance, RMSEA ≤ 0.08, CFI ≥ 0.95, and WRMR < 0.9.[41] Modification indices (MI) were used to address potential error correlations, allowing for theoretically justified adjustments to improve model fit.[42] These steps followed established best practices in psychometric validation, ensuring robustness in evaluating the scale's internal structure. Convergent and divergent validity were examined through correlations between FCR7 and validated scales Pearson's coefficient was used for normally distributed variables, and Spearman's coefficient for non-normal distributions.[36] Correlation strength was categorized as weak (0.0 - 0.3), moderate (0.3 - 0.7), or strong (0.7 - 1.0).[36] The choice of variables and measures to use was based on the previous studies of FCR7. For concurrent validity, FCR7 was hypothesized to correlate positively with the anxiety subscale of the HADS scale. For divergent validity, a weaker negative correlation was expected between FCR7 and QoL measured by the QLQ-C30 scale.[24,28] A receiver operating characteristic (ROC) analysis determined the cut-off score. This analysis evaluated the area under the curve (AUC), sensitivity, specificity, and predictive values, with AUC > 0.5 considered acceptable.[36] The optimal cut-off was identified based on the balance between sensitivity and specificity and their alignment with the AUC value.[36] This methodological approach is widely recognized for its application in health-related scale validation.[43] Finally, FCR levels among AYAs were analyzed descriptively, including the total FCR7 score and the proportion of participants in clinical and non-clinical categories based on the established cut-off. The inclusion of additional references ensures that the methodological approaches used were robustly justified and aligned with contemporary psychometric research.

Statistical power analysis

A post-hoc power analysis was conducted to verify that the sample size of 92 participants was sufficient for the statistical tests performed. The analysis was conducted using G*Power software, with a significance level of p = 0.05, a desired statistical power of 0.80, and an effect size based on Cohen's (1988) guidelines.[50] The results demonstrated that the sample size met the required statistical power (> 0.80) for all analyses, ensuring the robustness and reliability of the study's findings. These outcomes support the validity of conclusions drawn from the CFA model fit indices, ROC classification accuracy, and correlation assessments, confirming the study's ability to detect large to medium effect sizes.

RESULTS

Patient and public involvement

Patient and public involvement contributed to the study by improving study materials. Based on the feedback received from patients and the public, improvements were made to the information provided to participants: information was added that the study was being carried out in collaboration with two national organizations, and it was added that there could be a second participation if participants wanted it. Some feedback was also received regarding the FCR7 scale. Item four was considered difficult to interpret since the expression was not commonly used in Portuguese. As for item six, they suggested substituting "physical signs" for "physical symptoms". During the second pilot study, the wording of these items was improved so it was more straightforward for Portuguese speakers, ensuring face validity. This led to some delays in the study and required additional time from the research team.

In the sociodemographic status and clinical questionnaire, removing the option "palliative care" from treatment status, and giving the chance to add more details to the time since the diagnosis question was suggested. They also indicated that the sociodemographic and clinical questionnaire should appear after the information sheet and before the remaining scales. Additionally, it was defined that participants who contacted the researcher due to emotional reactivity to the study could be referred to Acreditar, which could provide the necessary support. Patients and the public also suggested that the word "cancer" should be substituted for

"oncologic disease." This expression is not commonly used in English, but it was considered a better word for the Portuguese version since some young people could be sensitive to the word "cancer", which has a stronger negative connotation in Portuguese.

Preliminary analysis: item properties

A preliminary data analysis showed that all possible Likert scale response values were observed for each item. The results indicated that the FCR7 scale had a good internal consistency (α = 0.89), and there was a low variation in Cronbach's alpha if items were deleted. All inter-item correlations were positive and higher than 0.30 and lower than 0.82, suggesting the absence of multicollinearity. The item-total correlations of the scale were higher than 0.40. An assessment of normality revealed that the kurtosis and skewness scores for each item were between -2 and 2[45] (Table 3). Based on this analysis, all FCR7 items were retained in the following steps.

Factorial validity

The internal structure of the FCR7 scale was assessed using a CFA. The original unidimensional model showed a significant misfit, as indicated by a significant χ^2 test and RMSEA above the recommended threshold: $\chi^2(14) = 64.22$; $p < 0.001$; $\chi^2/df = 4.59$; RMSEA = 0.20; 95% CI [0.15 - 0.25]; CFI = 0.98; WRMR = 0.59. These results suggested that the responses to the items might be influenced by additional factors beyond the proposed single factor. To explore potential sources of misfit, modification indices were analyzed. A significant residual correlation was identified between items 4 ("There are times when I have strong feelings about cancer possibly returning") and 5 ("I think about cancer possibly returning even when I don't want to"). Both items address emotional and cognitive concerns related to the possibility of cancer recurrence. Specifically, item 4 emphasizes intense feelings about the potential recurrence, while item 5 highlights intrusive thoughts even when undesired. This thematic similarity reflects a shared psychological nature commonly associated with the fear of recurrence, which may lead to residual variance not fully explained by the general factor. Based on this evidence and previous literature, such as the study by Lee *et* al,[28] the residuals of items 4 and 5 were allowed to correlate in the adjusted model. This modification is theoretically justified as it respects the construct's coherence and improves the fit indices without compromising the scale's unidimensionality. The modified model showed a significant improvement in fit indices: $\chi^2(14) = 33.60$; $p = 0.001$; $\chi^2/df = 2.6$; RMSEA = 0.13; 95% CI [0.07 - 0.19]; CFI = 0.99; WRMR = 0.38. Although the RMSEA continued to indicate a mediocre fit, the values of χ^2/df, CFI, and WRMR suggested an overall satisfactory fit. The residual variance shared between items 4 and 5 allowed in the adjusted model was consistent with the theory and supported the construct validity of the adjusted model, despite the potential impact of the sample size on the RMSEA results. The standardized factor loadings of the item parcels are presented in Fig. 1.

Convergent and divergent validity

As expected, the FCR7 total score showed a moderate positive correlation with anxiety (r = 0.45, $p < 0.001$), confirming convergent validity. No significant correlation was found between FCR7 and depression. This confirms that the FCR construct is distinct from depression. As for the quality of life, only emotional functioning had a weak negative correlation with FCR (Table 4). No significant correlations were found with total QoL, physical functioning, and cognitive functioning, confirming divergent validity.

Receiver operating characteristic curve analysis

Following the Peng *et al*[47] procedure, AYAs were categorized into two groups according to their HADS anxiety scores: clinical levels of anxiety (scores ≥ 8) and non-clinical levels (scores < 8). Using these scores as a classification criterion, the area under the curve of the ROC analysis was 69% ($p < 0.003$; 95% CI = 0.581 - 0.793), suggesting an acceptable level of diagnostic accuracy (Fig. 2). A cut-off score for FCR7 of ≥ 19.5 (19/20) appeared to be the best score to differentiate individuals between clinically significant levels

Table 3 – Descriptive statistics: item properties and reliability

FCR7 items	Min. - Max.	Median	Skewness	Kurtosis	Corrected item-total correlation	Cronbach's alpha of item deleted
Item 1	1 - 5	4	-0.716	-0.319	0.760	0.872
Item 2	1 - 5	3	-0.255	-0.553	0.792	0.870
Item 3	1 - 5	3	-0.233	-0.634	0.832	0.866
Item 4	1 - 5	3	-0.084	-0.601	0.813	0.868
Item 5	1 - 5	3	0.063	-0.977	0.851	0.861
Item 6	1 - 5	3	-0.102	-0.974	0.416	0.905
Item 7	0 - 10	5	-0.121	-0.762	0.812	0.898

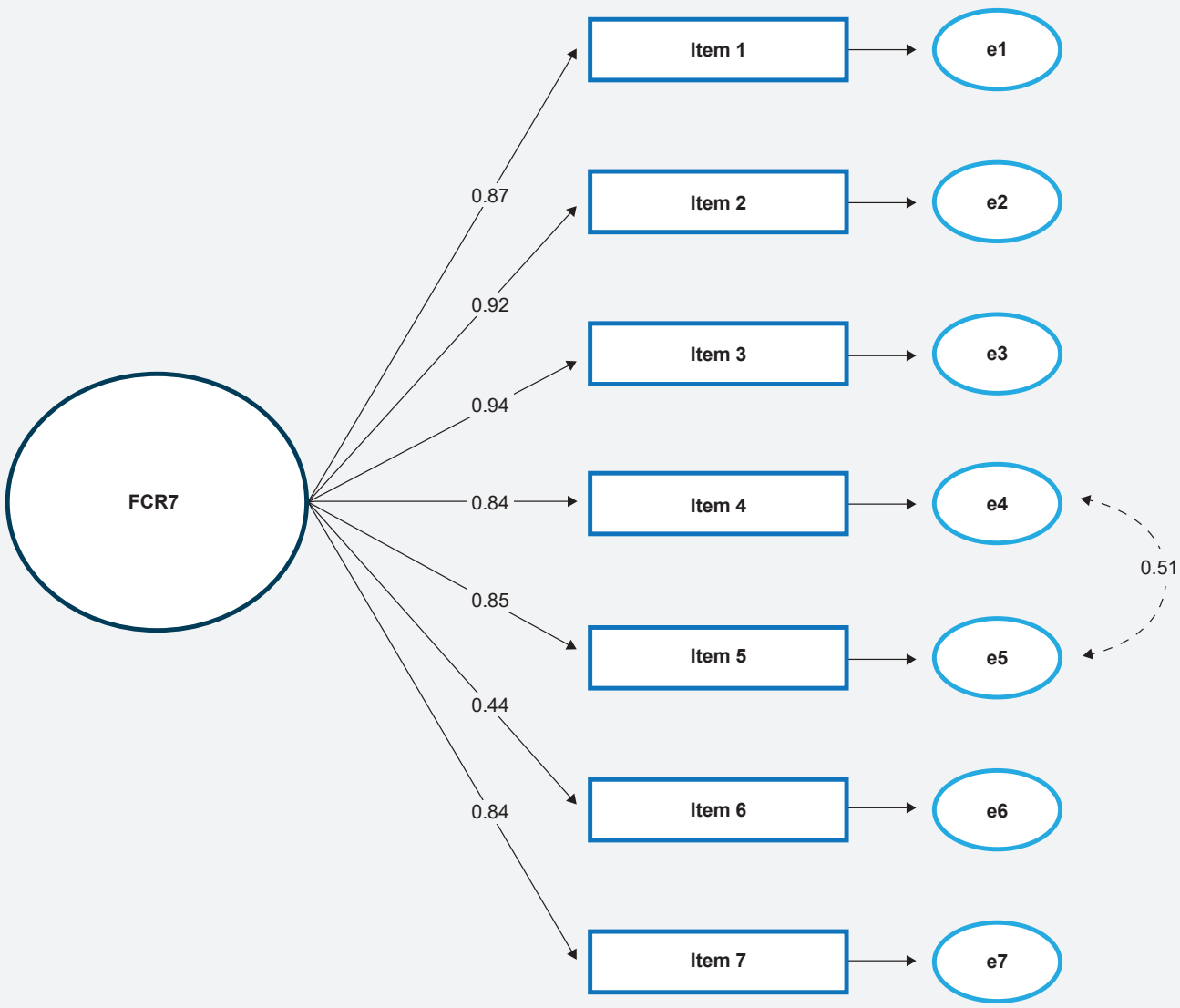

Figure 1 – Results of the confirmatory factor analysis for the Portuguese version of the FCR7

of FCR (FCR7 ≥ 20) and non-clinical levels (FCR7 ≤ 19), with a sensitivity of 77.2% and a specificity of 42.9% (PPV = 68.8%; NPV = 53.6%).

FCR levels

The FCR total score and levels of FCR were assessed. The total score shows that the mean severity for FCR among AYAs was 24.20. Considering a cut-off point of ≥ 20, 64 participants (69.6%) reported clinically significant levels of FCR, while only 28 participants (30.4%) reported non-clinical levels (Table 5).

DISCUSSION

This study's main aim was to validate the FCR7 scale for the Portuguese population of AYAs. We observed that FCR7 has a good model fit and reliability. Convergent and

Table 4 – Correlations for validity analysis

	Anxiety	Depression	Quality of life	Emotional functioning	Physical functioning	Cognitive functioning
FCR	0.45***	0.20	0.01	-0.33**	-0.18	-0.19

***: $p < 0.001$;
**: $p = 0.001$.

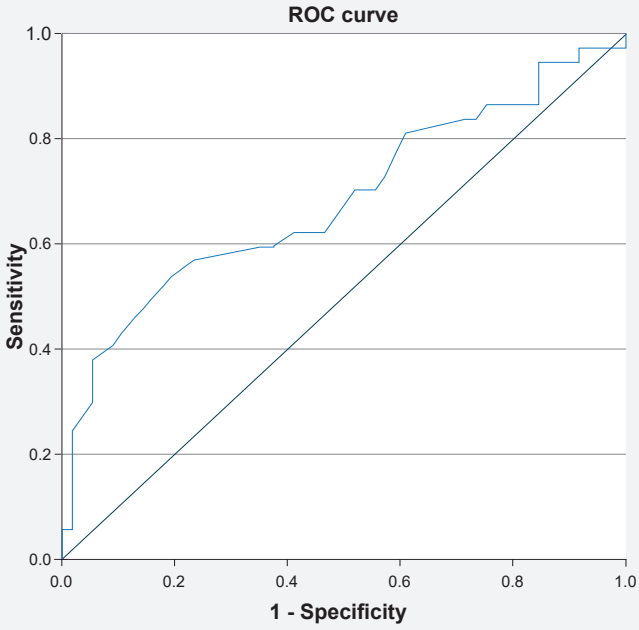

Figure 2 – Receiver operating characteristics (ROC) curve for the FC

divergent validity were also confirmed. This suggests that FCR7 is an excellent measure to assess FCR levels among Portuguese AYAs. Results also showed that almost 70% of the participants experienced clinically significant levels of FCR.

A good model fit was found for the FCR7 among Portuguese AYAs. These findings align with what was previously found with other versions of this scale.[24,25,27] The model fit was not perfect, but the results were acceptable after adjusting for modification indexes. As for the reliability analysis, the scale also showed good results. This concurs with previous studies focused on adults,[24,25,27] where good reliability was also found. These findings indicate that the FCR7 is reliable for assessing FCR levels among Portuguese AYAs with cancer. The unidimensionality of FCR7 was also confirmed since the scale showed good model fit and reliability results.

As expected, there were significant moderate correlations between anxiety and the FCR7 and moderate negative correlations between emotional functioning and FCR7. The previous validations of these scales found identical results,[24,25,27] supporting the good convergent validity of FCR7. In the literature, AYAs with high FCR levels were also found to experience high anxiety levels compared to AYAs with low FCR.[10] Regarding divergent validity, it was also confirmed. Although the total quality of life did not show a significant negative correlation with FCR as expected, the FCR7 scale did show a significant negative correlation with

Table 5 – Levels of FCR among Portuguese AYAs

FCR7	n	%	Range	Mean	SD
Total score			6 - 40	24.20	8.06
Non-clinical levels of FCR	28	30.4			
Clinical levels of FCR	64	69.6			

emotional functioning. This result is aligned with previous studies with AYAs, where a negative correlation between emotional functioning and FCR was also found.[49,50]

A cut-off score of 20 or higher was found to be indicative of clinically significant levels of FCR. Only the original version of the FCR7 scale has previously explored cut-off points for moderate and high levels of FCR. The authors have found that scores of 17 or higher indicated moderate levels of FCR, while scores of 27 or higher indicated high levels.[24] These cut-off scores are similar to the ones we found for clinical and non-clinical levels, supporting it.

The ROC analysis revealed a cut-off score of FCR7 ≥ 19.5 as the optimal threshold to differentiate between clinically significant and non-clinical levels of FCR, with an AUC of 69% ($p < 0.003$; 95% CI = 0.581 - 0.793). Our findings showed a sensitivity of 77.2% and specificity of 42.9%, indicating that this cut-off effectively identifies 77.2% of AYAs with clinical FCR (true positives) and 42.9% of AYAs without clinical FCR (true negatives). These results suggest that the cut-off score is more proficient in detecting positive cases of clinical FCR among AYAs than in accurately identifying negative cases. While these findings are promising, it is crucial to acknowledge that the specificity value is relatively low, which may result in a higher rate of false positives. Therefore, we recommend that future research should confirm these results with larger sample sizes and incorporate a gold standard measure, whenever feasible, to improve the robustness and diagnostic accuracy of the FCR7 cut-off point. Such validation would ensure stronger clinical utility and enhance the precision of FCR screening tools for AYAs.

It was also found that almost 70% of participants have clinically signficant levels of FCR. These results align with what has been found in the literature on AYAs.[10,21] Additionally, in the other validation articles of the FCR7 scale, adults with cancer experienced lower levels of FCR.[27,29] This aligns with the literature suggesting that AYAs experience higher FCR levels than older cancer patients and survivors.[3,7,8] In conclusion, these results suggest that FCR is an important concern among Portuguese AYAs.

Lastly, as reported by other studies,[52] PPI also helped improve this study. By involving cancer survivors and members of an association focused on young people with cancer before data collection, there was a chance to make the study more tailored and adequate for AYAs. Identifying difficulties in understanding some items of the FCR7 scale

also allowed for a better translation of the scale. Despite the positive effects, involving patients and the public also led to some delays in the project, requiring additional tasks and time from the research team. However, the benefits suppressed the challenges faced.

Some limitations can be pointed out. First, there is no gold standard measure to assess FCR, which limits the cut-off score analysis. Creating a gold standard measure for FCR would facilitate the establishment of cut-off scores among all the FCR measures. Second, the measures we used to assess anxiety and depressive symptoms, and quality of life were validated for adults only. Since our study included some participants under 18 years of age at recruitment, it is possible that these measures were not the most suitable for those participants. Our sample was also composed mostly of female participants and patients no longer in active treatment. One possible explanation is that these people are more willing to participate in research. However, this limits our understanding of the male population and those still in active treatment. Lastly, even though the sample size was adequate for the number of items on the FCR7 scale, a higher sample size could have provided more robust results.

A brief measure to assess FCR valid for AYAs in Portugal is an asset for national healthcare professionals and researchers. Healthcare professionals can now screen AYA cancer patients in clinical settings and refer patients with high FCR levels to receive psychological support. Evidence shows that FCR increases healthcare use and that FCR-focused interventions may be cost-effective.[51] Therefore, by adding FCR7 to clinical guidelines to identify AYAs with clinical FCR and referring them to psychological services to get the needed support, it is possible that it could have an economic impact by reducing costs. Researchers can also include FCR assessment more frequently in their research since the small number of items won't be an extra burden for participants. It can improve the identification of patients in need of psychological support and increase the literature on FCR, allowing us to understand it and its impact better.

CONCLUSION

This study is the first attempt to validate a scale to assess FCR levels among AYAs. Our preliminary results suggest that FCR7 is an adequate measure to assess FCR levels among Portuguese AYAs. Researchers all over the world should make efforts to validate scales to assess FCR among these young patients. This would improve the comparability of the results between studies and guarantee that the measure used to determine FCR levels is adequate for that specific population. Our study shows that the FCR7 scale is an excellent candidate to be validated by other researchers.

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AUTHOR CONTRIBUTIONS

MCN: Study design, literature review, study dissemination, data collection and analysis, writing of the manuscript.

CMDS, JBP, SM: Study design, supervision, critical review of the manuscript.

JO: Study dissemination, data collection.

AB: Data analysis, writing and critical review of the manuscript.

All authors approved the final version to be published.

PROTECTION OF HUMANS AND ANIMALS

The authors declare that the procedures were followed according to the regulations established by the Clinical Research and Ethics Committee and to the Helsinki Declaration of the World Medical Association updated in October 2024.

DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

COMPETING INTERESTS

The authors have declared that no competing interests exist.

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