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Fear of cancer recurrence, distress, and quality of life in adolescent and young adult cancer survivors

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Abstract: Adolescents and young adult cancer survivors often experience high levels of fear of cancer recurrence (FCR), which significantly impacts their emotional well-being and quality of life. The lack of studies on this target population in Portugal leads to a gap of knowledge that informs the development of interventions and solutions aimed at AYA cancer survivors. This study aimed to analyze the moderating effect of FCR on the relationship between emotional distress and quality of life in AYA surviving cancer. This is a cross-sectional study including 96 participants between the ages of 15 and 25 at the time of diagnosis. Sociodemographic, clinical, and psychosocial characteristics were collected through a sociodemographic and clinical questionnaire, the FCR7 scale, the Hospital Anxiety and Depression Scale (HADS), and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30). We analyzed correlations between FCR and clinical, sociodemographic factors and tested the direct and indirect relationships between FCR, distress, and quality of life. The results indicated that high levels of FCR were associated with lower emotional functioning, and gender was the only sociodemographic variable significantly associated with FCR. Although anxiety was found to influence emotional functioning in AYAs, FCR did not moderate the relationship between anxiety and emotional functioning. This study allows us to gain more knowledge about the psychological impact of the disease on this population.

Keywords: fear of cancer recurrence; adolescents and young adult; distress; anxiety; emotional functioning; quality of life

1. Introduction

Cancer is considered the second most common cause of death globally, responsible for the death of 9.6 million people in 2018 [1,2]. Research on Fear of Cancer Recurrence (FCR) has primarily focused on the adult population, consistently showing that FCR is associated with poorer psychological functioning and reduced quality of life, particularly among younger adults [3–5]. Studies indicate a strong association between high levels of FCR and symptoms of anxiety and depression in adult cancer survivors: 84% report elevated anxiety and stress, with younger survivors showing higher anxiety than older ones, and 66% reporting high levels of depression associated with FCR [3–10]. FCR in this group is defined as persistent and intrusive

worries about the possibility of the disease returning or progressing [1,11–15]. This fear can manifest across a continuum, from moderate levels of concern to severe, maladaptive distress that substantially disrupts daily life. FCR also significantly impacts quality of life. For example, Handschel et al. [16] and Chen et al. [17] found that 80% of participants experienced FCR and that greater levels of FCR were associated with lower self-reported quality of life and more negative expectations about the future. Furthermore, FCR tends to hinder psychosocial adjustment, particularly in younger individuals when compared to older adults, and is consistently associated with higher levels of anxiety and depression [18].

Among younger individuals, adolescents and young adults (AYAs)—those diagnosed with cancer between the ages of 15 and 39 [19,20]—represent a particularly vulnerable group. Cancer continues to be one of the leading causes of death in AYAs, and Portugal holds the position of the sixth European country with the highest incidence rates in those aged 15 to 29 and eighth in mortality rates [21]. Cancer has a significant impact on the mental health of AYA survivors, who are frequently affected by psychological difficulties. Approximately one in three AYAs experiences anxiety, and one in four deals with depressive symptoms, demonstrating the urgent need for customized psychological care interventions [22–24].

One of the main concerns among AYAs is FCR. The literature indicates that the majority of AYA cancer survivors report high levels of FCR. Luigjes-Huizer et al. [25] found that between 39% and 97% of survivors reported some degree of FCR, with 22% to 87% experiencing moderate levels and up to 15% reporting high levels of FCR. Similar findings have been reported in other studies, with high FCR impacting between 20% and 74% of cancer survivors [6,7,26,27]. FCR is a complex and multidimensional experience, influencing emotional states, cognitive processes, perceptions, and behaviors [11,12] levels of FCR.

Despite the limited number of studies focused exclusively on AYAs, existing evidence suggests that FCR has a substantial impact in this group. Higher levels of FCR among AYAs have been associated with greater psychological distress and anxiety, as well as a reduced quality of life [28]. FCR in AYAs has also been associated with a higher risk of psychological maladjustment and impaired well-being [28]. Moreover, Shay et al. [1] reinforce the association between elevated FCR and diminished quality of life. These findings reflect a consistent relationship between the fear and worry experienced by cancer survivors, without considering whether they are adults or AYAs [13,22]. Given the apparent increased vulnerability of younger individuals to the negative effects of FCR, it is important to further investigate its impact on AYA cancer patients. Even with the growing international research on this subject, in Portugal, there is a clear gap and possible absence of studies on symptoms of anxiety, depression, FCR, and quality of life in AYA. Considering this, it is pertinent to explore this association in terms of the national reality. The lack of studies on this target population in Portugal leads to a lack of knowledge on the part of society, hindering the development of interventions and solutions aimed at AYA cancer survivors. There is also a gap in the evidence on concerns related to the recurrence of the disease and the mechanisms leading to poor psychosocial adjustment. To fill these gaps, this study aims to: a) compare the psychosocial adjustment of AYAs with that of the validation sample of the measures used and b) analyze whether FCR moderates the relationship

between emotional distress and quality of life. This approach is intended to contribute to greater knowledge about the psychological impact of the disease on this population and potentially inform the development of more effective support strategies.

2. Materials and methods

2.1. Study design and participants

This cross-sectional study included a convenience sample of individuals aged between 15 and 54 years. The inclusion criteria for participation were: i) a previous diagnosis of cancer and ii) age between 15 and 25 years at the time of diagnosis. No time limits were imposed after diagnosis or stage of treatment, as the literature is inconsistent regarding the association between these variables and FCR [28].

2.2. Instruments

The sociodemographic questionnaire included questions regarding age, gender, nationality, marital status, education, and professional status, which made it possible to collect data about the sample. The clinical questionnaire made it possible to understand issues related to the diagnosis of cancer, namely age at diagnosis, time since diagnosis, type of cancer, stage and treatments, whether there had been a recurrence, as well as the perceived need for psychological support due to the diagnosis.

The FCR7 version [29] is a brief unidimensional scale that assesses levels of FCR. This instrument consists of 7 items, where the modality follows a Likert-type scale, with the first 6 items having a response from 1—never to 5—always, and item 7 with a response from 1—not at all to 10—very much, where higher scores represent a higher level of FCR. One example of an item is “I am afraid that my cancer may recur”. As far as internal consistency is concerned, this scale showed $\alpha = 0.89$ in the Portuguese validation [30], as was found in the present study.

The Hospital Anxiety and Depression Scale (HADS [31]; Portuguese version by Pais-Ribeiro et al. [32]) assesses emotional components in individuals with physical illnesses. This Portuguese version consists of 14 items, divided into two subscales, Anxiety and Depression, in which the modality follows a 4-point Likert scale (0–3). Individuals with scores above 11 have clinically significant symptoms [32]. 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. With regard to internal consistency, the anxiety and depression subscales had a value of $\alpha = 0.76$ and $\alpha = 0.81$, respectively [32]. In this sample, the anxiety and depression subscales showed good internal consistency ($\alpha = 0.88$ and 0.78 , respectively).

We also used the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core-30 (EORTC QLQ-C30 [33]; Portuguese version by Pais-Ribeiro et al. [34]), which assesses quality of life in cancer patients, consisting of 30 items distributed over 5 functional subscales, namely physical, role, cognitive, emotional, and social functioning [34]. 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. As for the response mode, a 4-point Likert scale was used (1—not at all to 4—very much), where high scores indicate a better quality of life and a high score on the symptoms scale reveals high levels of symptomatology. As for internal consistency, it has good values, from 0.74 to 0.81 [34]. In this study, the instrument showed good internal consistency ($\alpha = 0.91$).

2.3. Procedure

The study is part of the *Projeto Sem Medos*—What if cancer comes back?: “A family-centered adjustment to the fear of cancer recurrence in adolescents and young adults with cancer and their caregivers” (Ref. 2021.05418.BD), which aims to understand the adjustment processes of AYAs with cancer and caregivers to the FCR and is approved by the FPCEUP Ethics Committee (Ref. 2022/03-06c). Data was collected between November 2023 and February 2024 via an online questionnaire shared by national associations that support these patients, such as Acreditar, the Rui Osório de Castro Foundation, the Portuguese League Against Cancer, and on social networks such as Instagram, where influencers, groups, and forums were asked to help spread the word. Before taking part, all participants were given a detailed description of the study’s objectives and procedures on the first page of the questionnaire and were guaranteed voluntary participation in the study, as well as the anonymity and confidentiality of the data collected. Informed consent was obtained for all participants.

2.4. Data analysis

The statistical analyses were carried out using the Statistical Package for the Social Sciences (SPSS), version 29 [35]. Descriptive statistics (i.e., means, standard deviations, and frequencies) were used to summarize the participants’ sociodemographic and clinical characteristics. Difference tests (*t*-test) were also considered to compare the psychosocial adjustment of the present sample with the original validation samples of the measures used in this study. Pearson’s correlations were employed to assess the bivariate relationships between the sociodemographic and clinical variables and the FCR7, as well as the associations between FCR, distress, and quality of life. Additionally, based on the correlation analysis, a moderation model was conducted using the PROCESS macro for SPSS to explore the role of FCR as a moderator in the relationship between anxiety and emotional functioning. All analyses considered a significance level of $p < 0.05$.

3. Results and discussion

3.1. Characteristics of AYA

This study included a sample of 96 individuals aged between 15 and 54 years ($M = 26.04$; $SD = 6.7$; see **Table 1**), 83.3% females and 79.2% single. In terms of education, 36.5% of the participants completed a degree, and 45.8% were employed full-time. The most common diagnoses among the participants included Hodgkin's lymphoma (24%) and leukemia (19.8%), and 47.9% of the sample had undergone

surgery, 45.8% radiotherapy, and 80.2% chemotherapy. In this sample, the majority were no longer undergoing treatment (69.8%), and the diagnosis had occurred, on average, approximately 6 years ago (range: one month to 39 years). Most of the participants had not had a relapse (83.3%), nor had they been followed up psychologically (53.1%). Among our participants, 68.8% of AYAs were found to have clinically significant levels of FCR. Compared to the sample used for the original validation of the FCR7 scale [29], the participants included in this study reported significantly higher levels of FCR ($M = 24.02$; $t = 17.82$; $p < 0.001$). Regarding levels of anxiety and depression, the results indicated that 40.6% of the participants showed significant levels of depressive symptoms. It was found that the levels of cognitive functioning ($M = 68.58$; $t = -3.24$; $p = 0.002$), social functioning ($M = 63.02$; $t = -4.38$; $p < 0.001$), and overall quality of life ($M = 33.16$; $t = -13.77$; $p < 0.001$) of the AYA were significantly lower compared to the sample of adult cancer patients used to validate the EORTC QLQ-C30 [34].

Table 1. Sociodemographic and clinical characteristics ($n = 96$).

Characteristics	<i>n</i>	%
Sociodemographic		
Age ($M \pm SD$)	26.04 $\pm$ 6.7	
Diagnostic age ($M \pm SD$)	19.52 $\pm$ 0.39	
Gender		
Female	80	83.3
Male	16	16.7
Marital Status		
Single	76	79.2
The fact union	9	9.4
Married	10	10.4
Other	1	1
Education		
2nd cycle	1	1
3rd cycle	6	6.3
Secondary education	32	33.3
Graduate	35	36.5
Master	21	21.9
Doctoral	1	1
Work situation		
Student	31	32.3
Full-time employee	44	45.8
Part-time employee	2	2.1
Unemployed	11	11.5
Other	8	8.3
Clinic		
Time since diagnosis ($M \pm SD$)	5.93 $\pm$ 0.69	

Table 1. (Continued).

Characteristics	<i>n</i>	%
Type of cancer		
Leucemia	19	19.8
lymphoma of Hodgkin	23	24
lymphoma of non-Hodgkin	4	4.2
thyroid	6	6.3
brain cancer	8	8.3
testicular can	1	1
Skin cancer	2	2.1
Uterine	1	1
Other	32	33.3
Treatment status		
Active	25	26
It's no longer working	67	69.8
Other	4	4.2
Surgery		
Yes	46	47.9
No	50	52.1
Radiotherapy		
Yes	44	45.8
No	52	54.2
Chemotherapy		
Yes	77	80.2
No	19	19.8
Immunotherapy		
Yes	4	4.2
No	92	95.8
Hormonal therapy		
Yes	6	6.3
No	90	93.8
Recurrence		
Yes	16	16.7
No	80	83.3
Psychological support		
Yes	45	46.9
No	51	53.1

Note: N = frequencies; % = percentage of participants; M = mean; SD = standard deviation.

3.2. Correlations between FCR and clinical, sociodemographic factors

Bivariate correlations between clinical and sociodemographic variables revealed no significant relationships between fear of cancer recurrence (FCR) and factors such as age, treatment modalities (surgery, chemotherapy, radiotherapy, immunotherapy,

and hormone therapy), recurrence, disease status, and diagnostic timing ($p > 0.05$). However, a weak to moderate positive correlation was observed between FCR and the perceived need for psychological support. Additionally, a significant negative correlation was found between sex (0 = female, 1 = male) and FCR levels, suggesting that women report higher levels of FCR than men.

3.3. Testing the direct and indirect relationships between FCR, distress, and quality of life

A weak but significant positive correlation was found between the FCR and HADS-Depression scales and a moderate and significant positive correlation between the FCR and HADS-Anxiety scales ($r = 0.23$, $p = 0.0325$; $r = 0.46$, $p < 0.001$, respectively). Regarding the subscales of the QLQ, the emotional functioning subscale showed a strong negative correlation with anxiety and depression ($r = -0.75$, $p < 0.001$; $r = -0.63$, $p < 0.001$, respectively) and a moderate negative relationship with the FCR ($r = -0.37$, $p < 0.001$). In other words, higher levels of anxiety, depression, and FCR are associated with worse emotional functioning in the AYA sample. The other subscales used to assess functionality did not show a significant association with FCR, except for cognitive functioning, although the correlation was weak ($r = -0.22$, $p = 0.03$). Additionally, associations were found between the dimensions of quality of life and psychological distress. As for the physical functioning subscale, it showed a moderate negative correlation with anxiety and a strong one with depression ($r = -0.4$, $p < 0.001$; $r = -0.54$, $p < 0.001$). In other words, the higher the levels of anxiety and depression, the worse the participant's physical state. The cognitive functioning subscale shows a moderate negative correlation with depression ($r = -0.42$, $p < 0.001$). Role functioning, on the other hand, shows a weak negative correlation with anxiety and depression ($r = -0.3$, $p = 0.003$; $r = -0.45$, $p < 0.001$). Finally, the social subscale shows a moderate negative relationship with anxiety and depression ($r = -0.34$, $p < 0.001$; $r = -0.4$, $p < 0.001$, respectively) (see **Table 2**).

Table 2. Pearson correlations: Relationships between fear of recurrence, distress, and quality of life.

Variables	Mean $\pm$ SD	1	2	3	4	5	6	7	8	9
1. Emotional	60.76 $\pm$ 2.65	1								
2. Physical	81.18 $\pm$ 1.98	0.44**	1							
3. Cognitive	68.58 $\pm$ 2.95	0.43**	0.36**	1						
4. Role	75.52 $\pm$ 2.93	0.46**	0.67**	0.55**	1					
5. Social	63.02 $\pm$ 3.33	0.39**	0.43**	0.43**	0.66**	1				
6. QLQ	33.16 $\pm$ 2.09	-0.45**	-0.43**	-0.28**	-0.47**	-0.38**	1			
7. HADS-anxiety	8.11 $\pm$.42	-0.75**	-0.4**	-0.26**	-0.3**	-0.34**	0.28**	1		
8. HADS-depression	4.57 $\pm$.36	-0.63**	-0.54**	-0.42**	-0.45**	-0.40**	0.44**	0.65**	1	
9. FCR7	24.02 $\pm$.82	-0.37**	-0.18	-0.22*	-0.1	-0.18	0.03	0.46**	0.23*	1

Note: * $p < 0.05$; ** $p < 0.001$; SD = standard deviation.

Based on the correlation results, a simple moderation model was tested to explore the role of fear of recurrence as a moderator in the relationship between anxiety and emotional functioning. For this, the PROCESS macro for SPSS (version 4.2; Hayes,

2022) was used, specifically Model 1. The overall model was significant, explaining 54.4% of the variance in emotional functioning ($R^2 = 0.54$, $F(3,92) = 36.52$, $p < 0.001$), suggesting that the combination of predictor variables significantly contributes to variations in emotional functioning. However, the analysis of the interaction effect between anxiety and FCR indicated that the interaction was not significant ($F(1,92) = 0.07$, $p = 0.79$; CI 95% (-0.11; 0.09), suggesting that the impact of anxiety on emotional functioning did not vary significantly as a function of FCR levels in the present sample.

4. Discussion

This study aimed to analyze the moderating effect of FCR on the relationship between emotional distress and quality of life in AYA cancer survivors. Our results did not find a significant moderation effect of FCR, meaning that having a higher or lower level of FCR does not alter the relationship between anxiety and emotional distress. Previous studies showed that high levels of FCR are associated with lower emotional functioning [28]. Our results suggest that, despite the association between FCR and emotional distress, it is unclear how these two variables together lead to AYAs' emotional functioning. One possible explanation is that some additional variables may be influencing this mechanism. Further investigation is needed to find which variables these may be, and that may be important to tackle in future interventions to improve AYAs' emotional well-being. More specifically, regarding the relationship between anxiety and emotional functioning, our results showed that anxiety is related to emotional functioning, suggesting that high levels of anxiety can impair the emotional regulation and psychosocial adaptation of AYAs. However, it is important to consider that this relationship can be influenced by factors such as social support, coping strategies, stress levels, and individual characteristics such as resilience and self-esteem. In addition, sociodemographic variables such as age, gender, and stage of treatment can play a significant role in the intensity of this association [22,28], which is in line with previous studies [22]. High levels of anxiety may therefore be associated with a decline in the emotional functioning of AYAs. This negative impact can be explained by the effect of anxiety on mental health, which exacerbates stress and constant worry, resulting in a cycle of negative emotions. Such a relationship makes emotional regulation difficult and contributes to impaired psychological wellness, affecting the quality of life and the ability to cope with daily challenges [22]. Therefore, in order to develop effective interventions, it is essential to carry out further studies that explore how these factors interact and influence the emotional experience of AYAs. Understanding these dynamics will facilitate the creation of support strategies that are more specific and sensitive to the specific needs of this population [22,28].

Furthermore, in the correlation analysis, it was found that higher levels of anxiety, depression, and FCR are associated with lower emotional functioning, which is corroborated by the literature. FCR tends to trigger psychological and behavioral responses and is, therefore, related to high levels of anxiety and depression. These levels reflect the fear and worry experienced by cancer survivors [1,8,13,18,22,36].

This study identified an association between FCR and sociodemographic aspects, where gender was the only variable significantly associated with FCR. It was found that being female is associated with higher levels of FCR. One possible explanation for this is that, compared to young people in general, young women face additional challenges due to their stage of life, such as uncertainty about the future, interruptions in daily life, and continuing emotional development. In addition, these young women deal with issues specific to their emotional and social development, such as building a career, starting a family, and adapting to the responsibilities of young adulthood. These factors can make FCR even more difficult to cope with, as they feel that the illness could interrupt or negatively impact their future plans and dreams [37]. That said, some caution is needed when interpreting these results, since the sample studied is mostly female, which may have generated some bias in the results. Even so, these results are in line with those reported in other studies, which found that women report higher levels of FCR compared to men [9,38–40]. However, these results have the same limitation and risk of interpretation as this research, since the samples were mostly female [38]. In contrast to the present study, it is important to note that Cohee et al. [41] found that FCR levels were not associated with the female gender.

The limitations of this study relate to the fact that it is a cross-sectional design, which may limit the exploration of symptoms over time and will not allow causal associations to be established between the variables under study. The fact that the majority of the sample was female (83.3%) could bias the results. Consequently, the results should be interpreted with caution and cannot be generalized to all AYA cancer survivors in Portugal. Similarly, the fact that the results are based on self-report may also lead to recall bias.

In the future, it may be important to use a sample of AYA with a time limit after diagnosis to understand whether the limited or extended period of diagnosis influences the degree of FCR, since there are several articles that reveal inconsistencies on this parameter. Future research could consist of more extensive data collection to have a significant sample and be able to generalize the results to all AYA cancer survivors in Portugal. In addition, it would be relevant to integrate multidimensional data, such as medical records, caregiver reports, and physiological indicators, to complement the self-reports and improve the validity of the results. The analyses in the results should also take into account other variables, such as social support and coping styles, in order to clarify the moderating effects of FCR and provide a more complete understanding of the factors affecting the emotional experience of AYA. It would also be relevant to carry out a longitudinal study to assess the causal relationships between the levels of FCR, anxiety, and depression experienced by AYA or to examine the long-term evolution of the influence of FCR. In addition, it would be relevant for psychological interventions aimed at AYA survivors to be developed and evaluated for their viability and effectiveness in real contexts. Finally, it would be important to build specific programs for AYA in healthcare, including interdisciplinary teams that address needs specific to this age group, such as body image, infertility, the future consequences of cancer treatments and disease, possible entry into the job market, the risk of future pregnancies, and future quality of life.

This study has contributed to understanding the association between FCR, emotional distress, and quality of life in AYAs who have survived cancer. The results

showed that higher levels of FCR are significantly associated with higher levels of depression and anxiety, as well as lower emotional functioning. However, the moderation analysis of FCR on the relationship between anxiety and emotional functioning did not reveal a significant effect, suggesting that the influence of anxiety on this dimension occurs independently of FCR levels.

5. Conclusion

This study is the first attempt to understand whether high or low levels of FCR alter the relationship between anxiety and emotional functioning in AYAs. Our results suggest that FCR levels do not change the relationship between anxiety and emotional functioning in Portuguese AYAs. Researchers all over the world should look to better understand the relationship between FCR, psychosocial adjustment, and quality of life in AYAs. This would improve the comparability of results between studies and allow us to learn more about these aspects in this specific population.

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