Exploring the Fear of Cancer Recurrence (FCR) in caregivers of childhood cancer survivors in Singapore

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Abstract

Objective: Caregivers of paediatric cancer survivors often receive limited support and intervention to cope with the fear of cancer recurrence (FCR) in their children compared to those undergoing treatment. The study aims to investigate if caregivers continue to experience FCR even after their children have achieved remission.

Methods: Thirty caregivers from a local social service organisation were recruited and categorised into two groups based on the time since their child's last cancer treatment: ≤5 years (Group 1) and >5 years (Group 2). Data collected includes demographic details and responses from three questionnaires: State and Trait Personality Inventory (STPI), Fear of Cancer Recurrence Inventory (FCRI) caregiver version and a Risk Factor questionnaire, analysed using independent-samples T-test.

Results: Both groups experienced high FCR scores of 111.52(±14.29) and 94.44(± 24.01), p=0.073 for Group 1 and Group 2, respectively. Group 1 had higher level of cancer related triggers at 23.33(±4.13) as compared to Group 2 at 19(±4.97), p=0.04. There was no significant difference between the two groups in their STPI scores across all four subscales (p>0.05).

Conclusions and clinical implications: The study suggests that even as time passes, caregivers will continue to experience high level of FCR. Caregiver support after treatment should match the time since a child's last treatment, as Group 1 may require more acute support, while Group 2 may require support aimed at managing and reducing persistent FCR levels.

(221/250 words)

Introduction

In Singapore, cancer is identified as one of the principal causes of mortality.[1] Leukaemia, brain cancer, and lymphoma are the most prevalent types of cancer afflicting children.[2] An estimated 150 Singaporean children are diagnosed with cancer annually.[3] Despite considerable strides in early detection and therapeutic interventions due to medical advancements, the psychological repercussions of cancer persist for caregivers of childhood cancer, [4-6] especially the fear of cancer recurrence.

Fear of cancer recurrence (FCR) is defined as the fear that cancer may progress or recur.[7] Past studies have shown that FCR can be much more prevalent in caregivers than survivors.[8-9] The high prevalence of FCR has been associated with psychological problems such as emotional distress and poor quality of life.[10] The risk of adverse psychological effects persists for caregivers even five years post-recovery,[11-13] as they become more aware of the possibility of recurrence.[14] Caregivers, typically parents, deal with emotional scars from their child's cancer diagnosis, experiencing panic attacks and intrusive symptoms during the post-recovery period which are triggered by reminders of their child's diagnosis and flashbacks of stressful scenarios.[15] Even during their child's recovery phase, most parents do not believe their children have fully recovered.[16] Moreover, caregiving-related stressors such as financial burden and time-burden contribute to FCR,[17] affecting the quality of life,[18] social and mental well-being of caregivers.[19] Interpersonal support from family and friends provides limited relief,[20] and parents often experience reduced support after treatment, leading to feelings of loneliness.[15]

Extensive literature review supports the necessity of intervention for caregivers whilst their family members undergo active cancer treatments.[25-27] However, most of these studies were conducted in the Western societies[28]. While there are more literature[29-30] on supports rendered to children who are in treatment, there is a limited number of studies focus on theoretical framework for developing interventions tailored to caregivers of paediatric cancer patients on remission. On the other hand, the handful of local studies predominantly delve into the experiences of cancer patients during their cancer journey or examine FCR in cancer survivors.[31-33]

The present study takes another perspective by centring on caregivers, specifically those caring for children who have completed treatment and are now in remission. By shifting the spotlight to this often-overlooked group, we aim to investigate if caregivers continue to experience FCR even after their children have achieved remission. It also aims to explore personality traits and risk factors that contribute to FCR experienced by this group of caregivers.

Methods

Study Design & Participant Groups

This study was approved by the local ethics review committee. Caregivers registered with a community-based social service organisation that provides support to cancer patients and their families were invited to participate. Inclusion criteria were caregivers: (1) with children aged 21 years and below who had been diagnosed with cancer and had completed active cancer treatment or on cancer remission, and (2) who were proficient in English or Malay. Exclusion criteria included caregivers: (1) who were suffering from psychiatric illness or cognitive impairment, (2) who had substance abuse in the preceding 12 months, or (3) who were diagnosed with anxiety disorder or other mood disorders as indicated in their records.

All caregivers provided written informed consent before participation. Each participant was given three sets of questionnaires to complete: State and Trait Personality Inventory (STPI), Fear of Cancer Recurrence Inventory-caregiver version (FCRI-c), and Risk Factor Questionnaire that was developed by this study group. These questionnaires were administered by a study investigator in a face-to-face setting either at the study centre or the participants' home. Participants were encouraged to complete the questionnaires independently and provide their responses. For those requiring translation, the study investigator assisted by explaining the questions as needed.

Measures

Fear of Cancer Recurrence Inventory-caregiver version (FCRI-c). FCR was measured using the FCRI-c.[34] It contains 42 items separated into 7 subscales: triggers, severity, psychological distress, functional impairment, insight, reassurance, and coping strategies. Items were scored on a five-point Likert scale with 0 being 'Not at all' and 4 being 'A great deal' or 'All the time'. A higher score indicates higher FCR. The scale has been validated among caregivers and exhibits good internal consistency reliability.[34]

Fear of Cancer Recurrence Inventory – Short Form (FCRI-SF). The FCRI-SF[35] is a 9-item tool assessing the presence frequency, intensity, and duration of thoughts associated with FCR. Total scores range from 0 to 36 with higher scores indicating higher FCR. The FCRI-SF has shown high internal consistency (α=0.95), temporal stability (r=0.89), and construct validity.

State and Trait Personality Inventory (STPI). Personality traits was measured using State and Trait Personality Inventory (STPI) (Form Y).[24] It contains 80 items separated into 8 subscales: state and trait anxiety, state and trait anger, state and trait curiosity, and state and trait depression. 'State' items measure the participant's current emotional state while 'Trait' measures the participant's emotional disposition. Items were scored on a four-point Likert scale with 1 being 'Almost Never' and 4 being 'Almost Always". The psychometric properties of the scale have been widely established, demonstrating excellent internal consistency reliability for both state and trait subscale.[36]

Risk Factor Questionnaire. A risk factor questionnaire was designed to identify the factors affecting caregiver's FCR. It contains 13 items separated into three subscales: emotional stress, financial and medical (Appendix A). Participants selected 'Yes' or 'No' for each question listed.

Data Analysis

Demographic data such as age, sex, nationality, and education level were collected from participants with the questionnaires. Categorical variables were expressed in counts and percentages (n, %) and compared using the Chi-square test or Fisher's Exact test. Continuous variables were expressed in mean and standard deviation (SD) and compared using the independent-samples T test. Data analysis was conducted using the SPSS software Version 26 (IBM Inc., Chicago, IL, US), with statistical significance defined as p-value of <0.05.

Results

Between March and May 2023, a total of 35 caregivers were recruited into this study. However, 5 participants were excluded from the final analysis because they did not meet inclusion criteria. Data were analysed by separating caregivers into two groups according to the time since their child completed their last cancer treatment: ≤5 years (Group 1) and >5 years (Group 2). Table 1 illustrates the demographic and characteristics of the two caregiver groups.

Table 1: **Demographic and characteristics of caregivers**

Variable	Group 1: ≤5 years since child's last treatment (n=21)	Group 2: >5 years since child's last treatment (n=9)
Age (years)	44.57 ± 8.22	46.22 ± 8.20
Sex		
Male	7 (33%)	2 (22%)
Female	14 (67%)	7 (78%)
Nationality		
Singaporean	19 (90%)	8 (89%)
Singapore Permanent Resident	2 (10%)	1 (11%)
Education level		
Secondary and below	14 (67%)	6 (67%)
Tertiary	7 (33%)	3 (33%)

Fear of Cancer Recurrence (FCR)

In general, Group 1 was observed to have higher mean scores across all seven FCR subscales and total score of FCRI-c. Group 1 had statistically significant higher 'Triggers' subscale score than those in Group 2 (23.3±4.13 vs. 19±4.97, p=0.039) (Table 3).

Table 2: Caregivers' Fear of Cancer Recurrence (FCRI-c)

Domain (Total score)	**Group 1: ≤5 years since child's last treatment**	**Group 2: >5 years since child's last treatment**	***p*- value**
Triggers (32)	23.33 ± 4.13	19 ± 4.97	0.039
Severity (36)	22.14 ± 4.34	19.22 ± 6.00	0.212
Psychological distress (16)	9.76 ± 3.74	8.33 ± 4.42	0.411
Functioning impairments (24)	13.90 ± 6.33	12 ± 7.31	0.508
Insight (12)	7.14 ± 2.69	4.89 ± 3.72	0.127
Reassurance (12)	8.81 ± 2.91	7.22 ± 4.21	0.3234
Coping strategies (40)	26.43 ± 7.37	23.78 ± 7.79	0.400
Total score (172)	111.52 ± 14.29	94.44 ± 24.01	0.0734

Group 1 reported higher FCRI-SF score than Group 2, but this was not statistically significant (Table 3).

Table 3: Caregivers' Fear of Cancer Recurrence (FCRI-SF)

Group 1: <5 years since child's last treatment	**Group 2: >5 years since child's last treatment**	***p*-value**
22.14 ± 4.34	19.22 ± 6.00	0.143

State-Trait Personality Inventory (STPI)

There was no significant difference between the two caregiver groups in their STPI scores across all four subscales (p>0.05) (Table 4).

Table 4: Caregivers' State-Trait Personality Inventory (STPI)

	Group 1: ≤5 years since child's last treatment		Group 2: >5 years since child's last treatment		*p*-value	
STPI subscale	State	Trait	State	Trait	State	Trait
Anger (Ag)	13.76 ± 5.20	20.43 ± 6.19	14 ± 4.03	18.67 ± 5.92	0.8937	0.472
Anxiety (Ax)	19.86 ± 5.77	21.10 ± 4.57	21.56 ± 5.27	18.22 ± 4.06	0.2293	0.105
Curiosity (Cy)	28.86 ± 3.88	27.57 ± 4.31	27.33 ± 4.09	26.89 ± 3.76	0.3581	0.668
Depression (Dp)	17.24 ± 5.92	17.67 ± 4.43	18.33 ± 6.61	17.11 ± 4.08	0.6748	0.743

Risk Factor Questionnaire

Table 5 shows the percentages of caregivers who answered ‘Yes’ for each item in the Risk Factor Questionnaire. In general, caregivers in Group 1 answered “Yes’ more frequently in the Emotional Stress and Financial domains than Group 2, but none of these were statistically significant.

Table 5: Risk Factor Questionnaire

Items	Group 1: ≤5 years since child’s last treatment	Group 2: >5 years since child’s last treatment	*p*-value
Domain 1: Emotional stress			
I blame myself if my child has a cancer relapse	8 (38.1%)	1 (11.1%)	0.1394
I would feel like I have failed my child if he/she has a relapse	12 (57.1%)	2 (22.2%)	0.079
I would feel like I did not adequately manage my child's health after cancer if he/she has a relapse	15 (71.4%)	3 (33.3%)	0.051
Stress is a contributing factor to my fear of recurrence for my child	13 (61.9%)	5 (55.6%)	0.745
I fear losing my child	19 (90.5%)	8 (88.9%)	0.894
I fear passing away before my child.	16 (76.2%)	7 (77.8%)	0.925
I do not want my child to be stressed.	20 (95.2%)	9 (100%)	0.506
It is an additional stress for the caregiver/me if my child has cancer again.	19 (90.5%)	8 (88.9%)	0.894
Domain 2: Financial			
Money is a contributing factor to my fear of cancer relapse for my child.	20 (95.2%)	8 (88.9%)	0.523
Loss of income is a contributing factor to my fear of cancer relapse for my child.	20 (95.2%)	8 (88.9%)	0.523
It is a financial worry to the family if my child has cancer relapse.	20 (95.2%)	8 (88.9%)	0.523
Domain 3: Medical			
I am worried my child will experience medical problems long after treatment ends (e.g., heart problems, bone problems).	19 (90.5%)	9 (100%)	0.338
I fear that the treatment might be unsuccessful.	19 (90.5%)	8 (88.9%)	0.894

Discussion

The present study is the first in Singapore to examine FCR in caregivers looking after children on cancer remission. Results showed that regardless of years of remission, caregivers experienced high level of FCR. In addition, caregivers who experienced cancer treatment with their child in relatively recent times had higher levels of cancer-related triggers.

The FCR scores in Group 1 (<5years) showed an upward trend when compared to Group 2 (<5 years), although this did not reach statistical significance (111.52±14.29 vs 94.44±24.01, p=0.073). This indicates that caregiver FCR could be higher in the immediate post-treatment period, resulting in a pronounced psychological impact during this phase. Compared to other studies with cancer patients of various types,[40] both caregiver groups in our study exhibited higher FCR scores than the weighted mean scores of 65.2. Local data further emphasizes this heightened FCR in our study as the average FCR score among Singaporean patients was reported to be 59.5 ± 30.4.[33] However, it is important to note that these FCR scores are from patients and not caregivers, although another study[40] has shown comparable scores between caregivers and patients.

With both caregiver groups experiencing elevated FCR, attention turns to identifying a cut-off value for clinical level of FCR to pinpoint caregivers who may require targeted interventions. Previous studies have proposed a cut-off score of ≥13 on the FCR-SF domain as clinically significant for FCR. [40-41] Sub-analysis of the FCR-SF scores for both groups (22.14±4.34 vs 19.22±6.00) reveals that the caregivers in our study fall within the clinical range of having an FCR. This is consistent with other studies,[19,42-43] which reported moderate to high FCR and parental distress among participants. Moving forward, this cut-off value could be used by social services to screen and identify caregivers with clinical levels of FCR, and subsequently, prioritize interventions accordingly.

Additionally, there was a statistically significant difference in the FCR-Triggers domain, where Group 2 (>5 years) scored lower in comparison to Group 1 (<5 years). This suggests that caregivers whose child completed their cancer treatment more than 5 years ago were less emotionally reactive to cancer-related stimuli. Furthermore, both caregiver groups ranked Item 1 *("Television shows or newspaper articles about cancer or illness"*) and Item 3 *("My or his/her medical examinations, e.g., annual check*-up, blood tests, *X-rays"*) the highest in triggering an FCR. These findings align with a study[28] highlighting continuous exposure to these triggers serves as persistent reminder, reigniting concerns and rekindling the emotions associated with caregivers' initial experiences in the cancer journey.

Literature suggests that persistent FCR extends beyond the time delineation of treatment completions, with studies indicating that FCR may worsen over time, highlighting the enduring nature of emotional challenges faced by caregivers. [16, 50-51] While these insights are invaluable, it is essential to acknowledge potential cultural variations in our study samples compared to predominantly Western-centric studies. A local qualitative study[52] found that the experiences of Singaporean caregivers share universality with caregivers from other countries. However, distinctions arise in how caregivers internalise and cope with the situation. For instance, the study highlighted that caregivers inclined to compare their child's general functioning with other healthy children. Though speculative, this inclination may be influenced by the hyper-competitive culture in Singapore whereby children and parents alike feel the need to excel developmentally and academically.[53-54]

There are studies suggesting a link between personality traits and FCR although most of these studies are on cancer survivors.[21-23] Palas[21] found that non-modifiable characteristics such as neuroticism and conscientiousness may serve as risk factors for higher FCR whereas Butow[22] reported a relationship between one's metacognition and FCR. A meta-analysis of 34 studies[23] found that neuroticism, anxiety, and depression played a role in FCR. Considering traits as risk factors, the present study would incorporate the State-Trait Personality Inventory (STPI)[24] for a more targeted study between personality traits and FCR. The STPI would enable us to explore a range of personality factors that may contribute to FCR.

The data obtained from the present study indicates that irrespective of the time elapsed since the cancer treatment ends, caregivers of pediatric cancer survivors reported similar scores on the STPI subscales and overall scale. This may imply a uniform emotional response among caregivers, independent of their personality characteristics, resulting in an elevated FCR at time of the questionnaires administration. These results are consistent with a study[43] of caregivers of adult patients, where no correlation between state anxiety and trait anxiety scores was observed. The nature of caregiving is inherently stressful,[44] which may lead to persisting emotional impacts regardless of patient's disease stage or the time since treatment ended.[46-49]

Descriptive results from the Risk Factor Questionnaire underscore the substantial levels of worry experienced by both groups, encompassing emotional, financial, and medical-related concerns. Notably, our findings unveil a persistent emotional burden experienced by caregivers even beyond the immediate post-treatment period. Further analysis reveals that the caregivers in Group 1 (≤5 years) experience higher emotional stress than Group 2 (>5 years). Particularly, 57-72% of caregivers in Group 1 responded “Yes” to Item 2 *(“I would feel like I have failed my child if he/she has a relapse”*) and Item 3 *(“I would feel like I did not adequately manage my child's health after cancer if he/she has a relapse”*), compared to 20-33% in Group 2 (>5 years). These findings align with established associations between FCR, symptoms of depression, generalized anxiety, and death anxiety.[38] Another study which supported our finding, also showed a clinically significant level of FCRs among caregivers, where caregivers have an overarching sense of personal responsibility for the patient's life, fear of patient suffering, strong desire to protect, and unpreparedness and uncertainty on potential recurrence.[39]

Lastly, our observation from the center reveals a tendency for caregivers in Group 1 (≤5 years) to participation less in support groups, focusing more on their children as they gradually readjust to their altered circumstances. It has been further noted that caregivers in Group 1 (≤5 years) appear to derive greater benefit from individualised support and attention. On the other hand, caregivers in Group 2 (>5 years), despite having had a longer period to adapt to their altered circumstances, continue to experience elevated levels of FCR. Remarkably, this group is observed to be more inclined to participate in support groups. Therefore, it is posited that their continued engagement with these groups, coupled with additional resources aimed at managing and reducing persistent FCR levels, could be beneficial. Considering these findings, there is an intention to explore the development of specialised programs that amalgamate the advantages of group support with targeted strategies for FCR mitigation. This bifocal approach is designed to augment the overall well-being of caregivers in Group 2 by addressing emotional issues and cultivating a supportive community environment.

This study has several limitations. First, the small sample size of 30 caregivers, primarily representing Singaporean Malays, may limit the generalizability of the findings to individuals of different racial or religious backgrounds. Additionally, the unequal distribution of participants between both groups could affect the robustness of the results. This imbalance may be attributed to most Group 2 (>5 years) families moving on with their lives and no longer have affiliations with our organisations, especially in terms of financial assistance. They have likely achieved financial stability and adapted to a normal routine, which can explain their lowered recruitment rate in this study. Moreover, the sample consisted of participants from

Singapore, where advanced medical treatments are readily available and medical fees are heavily subsidised for citizens. This context may differ significantly in other industrialized countries where the health system, laws, and public policies may vary.

To address the limitation and enhance the current study's impact, future research could consider establishing collaborations with other paediatric cancer organizations serving similar populations. Such collaboration could facilitate data collection from a larger and more diverse sample, thereby enhancing the depth and breadth of understanding. By collaborating with a specific organization or institution, the findings of the study could directly inform the services provided to the targeted population. This could be achieved through the development of suitable interventions or support groups for caregivers of children who have completed treatment. An expanded sample size would also enhance the representativeness of the target population and strengthen the statistical significance and applicability of the results.

Additionally, incorporating qualitative methodologies, such as in-depth interviews, could provide insights into caregivers' experiences with FCR, uncovering emotional and cultural nuances that quantitative measures may overlook. This holistic approach would ensure more comprehensive understanding of caregivers of paediatric cancer survivors. Moreover, future studies could adopt longitudinal designs to capture caregivers' experiences overtime offering insights into the trajectory of FCR and its determinants post-treatment.

Conclusion

Irrespective of the duration since their children have attained cancer remission, the present research indicates that FCR remains clinically elevated in caregivers. This underscores the necessity for bespoke interventions for caregivers during the post-cancer treatment phase to enhance their quality of life throughout the cancer journey.

(2677/4000 words)

Disclosure Statement

The authors declare that there are no known conflicts of interest associated with this publication.

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Appendices

Appendix A

Measures/Instrument

Self-Generated Questionnaire

Domain 1: Self (Emotion/Stress)

1. I blame myself if my child has a cancer relapse.
2. I would feel like I have failed my child if he/she has a relapse.
3. I would feel like I did not adequately manage my child's health after cancer if he/she has a relapse.
4. Stress is a contributing factor to my fear of recurrence for my child.
5. I fear losing my child.
6. I fear passing away before my child.
7. I do not want my child to be stressed.
8. It is an additional stress for the caregiver/me if my child has cancer again.

Domain 2: Financial

1. Money is a contributing factor to my fear of cancer relapse for my child.
2. Loss of income is a contributing factor to my fear of cancer relapse for my child.
3. It is a financial worry to the family if my child has cancer relapse.

Domain 3: Medical

1. I am worried my child will experience medical problems long after treatment ends (e.g., heart problems, bone problems).
2. I fear that the treatment might be unsuccessful.

Appendix B

Results Table

Table 5: FCR Responses Between Male and Female Caregivers

Domain (total score)	Male caregivers	Female caregivers	*p*- value
Triggers (32)	23.56 ± 3.78	21.38 ± 5.06	0.2089
Severity (36)	23.11 ± 4.20	20.48 ± 5.16	0.1591
Psychological distress (16)	10.67 ± 4	8.76 ± 3.86	0.2462
Functioning impairments (24)	14.78 ± 5.89	12.71 ± 6.89	0.4151
Insight (12)	6 ± 3.28	6.67 ± 3.15	0.6134
Reassurance (12)	8.44 ± 3.28	8.29 ± 3.47	0.9065
Coping strategies (40)	24.33 ± 7.02	26.19 ± 7.74	0.5286
Total score (172)	110.89 ± 15.54	104.48 ± 20.42	0.3592

Table 6: Risk Factor Questionnaire responses between Male and Female Caregivers

Item	Male Caregivers	Female Caregivers	*p*-value
Domain 1: Emotional stress			
I blame myself if my child has a cancer relapse	5 (55.6%)	4 (19.0%)	0.0455
I would feel like I have failed my child if he/she has a relapse	4 (44.4%)	10 (47.6%)	0.8731
I would feel like I did not adequately manage my child's health after cancer if he/she has a relapse	6 (66.7%)	12 (57.1%)	0.6256
Stress is a contributing factor to my fear of recurrence for my child	6 (66.7%)	12 (57.1%)	0.6256
I fear losing my child	9 (100%)	18 (85.7%)	0.232
I fear passing away before my child.	5 (55.6%)	18 (85.7%)	0.0735
I do not want my child to be stressed.	9 (100%)	20 (95.2%)	0.5055
It is an additional stress for the caregiver/me if my child has cancer again.	9 (100%)	18 (85.7%)	0.232
Domain 2: Financial			
Money is a contributing factor to my fear of cancer relapse for my child.	8 (88.9%)	20 (95.2%)	0.5229
Loss of income is a contributing factor to my fear of cancer relapse for my child.	9 (100%)	19 (90.5%)	0.3379
It is a financial worry to the family if my child has cancer relapse.	9 (100%)	19 (90.5%)	0.3379
Domain 3: Medical			

I am worried my child will experience medical problems long after treatment ends (e.g., heart problems, bone problems).	8 (88.9%)	20 (95.2%)	0.5229
I fear that the treatment might be unsuccessful.	9 (100%)	18 (85.7%)	0.232

Table 7: Fear of Cancer Recurrence (FCR) According to Caregivers' Education Levels

Domain (Total score)	**Secondary education & below**	**Tertiary education**	***p*- value**
Triggers (32)	22.2 ± 4.23	21.7 ± 5.93	0.8152
Severity (36)	21.65 ± 5.09	20.5 ± 4.90	0.5572
Psychological distress (16)	9.3 ± 3.47	9.4 ± 4.95	0.9552
Functioning impairments (24)	13.45 ± 5.99	13.1 ± 7.96	0.904
Insight (12)	7.05 ± 2.91	5.3 ± 3.43	0.1862
Reassurance (12)	8.5 ± 3.14	8 ± 3.92	0.7302
Coping strategies (40)	26.1 ± 7.30	24.7 ± 8.10	0.6508
Total score (172)	108.25 ± 17.22	102.7 ± 22.83	0.5084