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Fear of cancer recurrence in caregivers of paediatric cancer survivors in Singapore

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Dear Editor,

More children now survive cancer, and their parents often continue to fear that the disease will return.[1] Fear of cancer recurrence (FCR) is a common unmet need in survivorship, but most studies measure it in survivors rather than caregivers. In a recent meta-analysis, caregivers reported similar levels of FCR to those of survivors, with about half of the caregivers experiencing clinically significant FCR, which was associated with depression and anxiety.[2] In paediatric cancer, these caregivers are usually parents. About half of the caregivers also reported dysfunctional fear of progression years after treatment ends,[3] and about one-third of adult childhood-cancer survivors still reported clinically significant FCR decades after the end of treatment.[4] Separate parent and child versions of the FCR Inventory now exist to evaluate the multidimensional aspects of fear, worry, and preoccupation regarding cancer recurrence or progression, reflecting its clinical relevance.[5]

In Singapore, FCR has been documented in adult survivors (43.6% clinical, 32.1% severe).[6] The authors are not aware of any study describing FCR in caregivers of paediatric cancer survivors in Singapore or elsewhere in Southeast Asia.[7] In this community-based Singapore sample, the authors aimed primarily to describe the magnitude and content of FCR among caregivers of paediatric cancer survivors. As a secondary, exploratory observation, the authors also examined whether FCR appeared to differ by time elapsed since the child completed treatment, while recognising that the cross-sectional design cannot establish how fear evolves over time within an individual caregiver.

This was a cross-sectional survey of caregivers of paediatric cancer survivors, carried out between March and April 2023 through Ain Society's Young Heroes Cancer Care, a community-based organisation in Singapore. Eligible participants were parents of children treated for cancer. The authors invited all eligible caregivers reachable during this period. Among 50 caregivers approached, 30 (60%) took part. Researchers with no conflict of interest administered the survey in person, clarified items, and checked each form to ensure there were no missing data. The survey covered demographics, the Fear of Cancer Recurrence Inventory-caregiver version (FCRI-c), and a self-developed risk-factor questionnaire.

The authors scored the 42-item FCRI-c using its original 7-factor structure,[8] with item 13 reverse-scored and total scores ranging from 0 to 172. The Severity subscale also serves as the FCRI Short Form, where a score of ≥13 indicates clinically significant FCR and ≥22 indicates high-specificity clinical FCR.[9] Caregivers were grouped according to the time since the child's last treatment, using a 5-year long-term-survivor threshold: ≤5 years (Group 1: n=18; 3.1 ± 1.6 years) and >5 years (Group 2: n=12; 9.3 ± 3.1 years; range, 5.1–17.0 years) (Table 1). Caregivers reported this in various formats, which the authors converted to elapsed years. Data were analysed using independent-samples t-tests. No a priori sample-size calculation was performed; the sample was simply the caregivers reachable through 1 organisation. The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (Supplementary Annex S1).

The 2 groups did not differ significantly on age, sex, or educational qualification (all $P>0.05$). No clinical data on the child's cancer (e.g. malignancy type, stage, treatment, complications, or secondary malignancy) were collected.

FCR was common among the caregivers. Overall, 96.7% of caregivers scored above the FCRI Short

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Table 1. Demographic characteristics and between-group FCRI-c comparisons (n=30).

Variables	Group 1: ≤5 years (n=18)	Group 2: >5 years (n=12)	*P* value
Age, mean ± SD, years	45.50 ± 8.43	46.92 ± 8.41	0.655
Female, no. (%)	11 (61%)	9 (75%)	-
Male, no. (%)	7 (39%)	3 (25%)	-
Tertiary education, no. (%)	6 (33%)	5 (42%)	0.712
Time since treatment, mean ± SD, years	3.1 ± 1.6	9.3 ± 3.1	-
Triggers, mean ± SD (maximum 32)	23.33 ± 4.13	19.00 ± 4.97	0.039
Severity, mean ± SD (maximum 36)	22.14 ± 4.34	19.22 ± 6.00	0.212
Psychological distress, mean ± SD (maximum 16)	9.76 ± 3.74	8.33 ± 4.42	0.411
Functioning impairments, mean ± SD (maximum 24)	13.90 ± 6.33	12.00 ± 7.31	0.508
Insight, mean ± SD (maximum 12)	7.14 ± 2.69	4.89 ± 3.72	0.127
Reassurance, mean ± SD (maximum 12)	8.81 ± 2.91	7.22 ± 4.21	0.323
Coping strategies, mean ± SD (maximum 40)	26.43 ± 7.37	23.78 ± 7.79	0.400
FCRI-c total, mean ± SD (maximum 172)	111.52 ± 14.29	94.44 ± 24.01	0.073

FCRI-c: Fear of Cancer Recurrence Inventory-caregiver; SD: standard deviation
FCRI-c subscale and total scores are presented as mean ± SD.
Group comparisons were conducted using independent-samples t-tests.
P<0.05 in bold was considered statistically significant.
The Triggers subscale result should be interpreted with caution given the modest and unequal group sizes as well as the number of comparisons performed. Replication in a larger sample is warranted. Effect sizes were not computed here but are recommended for future work.

Form cut-off score (≥13) and 50.0% scored above the high-specificity cut-off score (≥22). These proportions are higher than the survivor benchmarks of 53.9%/30.0%[9] and the 58.8%/19.2% for the FCRI Short Form cut-off score and high-specificity cut-off score, respectively, as reported in the largest known meta-analysis (n=9311),[10] although caregiver-specific norms are still scarce. The most endorsed fears were those that concerned the child, namely, sparing the child further treatment stress (96.7%) and losing the child (86.7%), followed by long-term medical problems (93.3%) and financial concerns (money as a source of fear, family financial worry, and loss of income; 86.7–90.0%).

In the exploratory comparison, Group 1 (≤5 years) had higher scores than Group 2 on every subscale and in the total (111.52 ± 14.29 versus [vs] 94.44 ± 24.01; *P*=0.073). The Triggers subscale, which assesses cues and situations that may prompt or intensify FCR, reached statistical significance (23.33 ± 4.13 vs 19.00 ± 4.97; *P*=0.039). The remaining subscales, including Severity, Insight, and Reassurance, did not reach statistical significance (ranging from *P*=0127 to *P*=0.508).

To the authors' knowledge, this is the first study to describe caregiver FCR in Singapore, a setting where caregiver-focused data have been lacking, even though the persistence of parental FCR after treatment is well documented in Western populations.[2-4] This study's data add to the understanding of caregiver FCR by showing that concerns extend beyond cancer recurrence to encompass potential long-term health consequences. Worry about long-term medical problems (93.3%) fits the documented burden of late effects among childhood cancer survivors treated in Singapore.[11] Fear of a second cancer, itself a late effect,[4] was not asked about separately and should be studied in future work.

Financial concerns, such as out-of-pocket treatment costs and loss of household income during a child's cancer treatment, may also influence caregiver FCR in Singapore. As these factors were not assessed in this study, the authors cannot determine whether they would help explain differences in caregiver FCR between Singapore and Western cohorts. The higher Triggers score in Group 1 may reflect greater early reactivity to cancer-related reminders such as routine body scans, which occur more often soon after treatment, though this study cannot confirm this. As these are between-group comparisons rather than repeated measures, and some Group 1 caregivers may still have been in active follow-up (clinical status was not recorded), the authors cannot separate recent

treatment from ongoing surveillance and treat these as preliminary signals for longitudinal work. In informal interactions with researchers, caregivers who seemed to be coping often mentioned "scanxiety" (a term that has come to refer to anxiety related to scanning procedures), though only when asked. They further described the pressure to be "strong and hoping for the best." While this is an informal observation and not a study measure, it shows how easily caregiver FCR can be missed without a simple screening approach.

The study has clear limitations. It is a convenience sample of 30 caregivers from 1 organisation. Caregivers engaged with a community support organisation may differ systematically from caregivers who do not seek support services, thus introducing self-selection bias. As such, the findings should be considered preliminary and hypothesis-generating. The sample size was too small (n=18 vs 12) to detect even large effects reliably; self-report is subject to recall and social-desirability bias; no clinical data were collected; and the cross-sectional design cannot show how FCR changes within an individual caregiver.

Clinically significant FCR was common in this community-based Singapore sample, extended beyond recurrence into concerns about long-term effects, and appeared higher earlier after treatment, although only Triggers reached significance. Larger, multi-site longitudinal studies in Singapore and the region are needed to map how caregiver FCR develops. Brief FCR screening within existing follow-up services (e.g. late effects clinics and community-based cancer organisations), with referral pathways, is a reasonable next step. However, its feasibility, outcomes, timing, costs, and acceptability to caregivers and clinicians should first be formally evaluated.

Supplementary material

Annex S1. STROBE checklist for cross-sectional studies.

Ethics statement

Ethics approval was obtained prior to data collection (NERC/002/2023). All participants provided written informed consent.

Declarations

The authors declare that they have no affiliations with or involvement in any organisation or entity with any financial interest in the subject matter or materials discussed in this manuscript. This study received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. The authors had full responsibility for the study design, data collection, analysis, interpretation, and manuscript preparation.

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