

Leveraging real-world data to develop long-term follow-up programmes for childhood cancer survivors

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In this issue of the *Annals*, Lam Shang Leen et al. comprehensively audited the late effects experienced by 485 childhood cancer survivors who visited the long-term follow-up (LTFU) clinic of KK Women's and Children's Hospital (KKH), Singapore between 2017 and 2023.¹ The authors found that approximately 80% of survivors had experienced at least 1 late effect. LTFU care, which emphasises the prevention, early detection and treatment of late effects, is an integral part of survivorship care for childhood cancer survivors.² However, most studies describing paediatric LTFU models and practices have been conducted in North America, Europe and Oceania. Consequently, there is a paucity of related studies conducted in Asia.^{3,4} This study represents one of the first reports to systematically evaluate the prevalence of late effects among childhood cancer survivors in Southeast Asia. One notable strength of this study is the use of a well-characterised cohort and the application of the Common Terminology Criteria for Adverse Events to identify and grade late effects, thus facilitating standardised data collection and cross-cohort comparability with similar international cohorts. The resulting data provide a regional benchmark for quantifying the burden of cancer- and treatment-related late effects in Southeast Asia, where the systematic surveillance of chronic health conditions among childhood cancer survivors remains limited.

Moreover, this study exemplifies how international survivorship guidelines can be locally adapted based on real-world evidence. Drawing on the findings from this cohort, the authors implemented a structured cancer- and duration-specific LTFU framework for KKH. They found that the onset of the first late effect occurred substantially later in leukaemia survivors (10–14 years post-diagnosis) than in survivors of central nervous system and solid tumours, who typically developed late effects within 5 years. By delineating the timings of onset and types of late effects across survivors, the authors could identify

the timing, frequency and duration of surveillance for each specific cancer diagnosis group, which in turn informed resource allocation and screening prioritisation. Similar adaptations driven by population data have been implemented in other countries. For example, valuable survivorship data from major multicentre, multidisciplinary childhood cancer cohorts in North America and Europe over the past 5 decades have led to important changes in clinical practice, particularly the development of LTFU surveillance guidelines and targeted interventions.⁵ In the UK, findings from the British Childhood Cancer Survivor Study delineate the excess risks of second malignancies and cardiovascular disease, thus influencing survivorship pathways within the National Health Service and contributing to national guidelines (SIGN 132).⁶ These experiences demonstrate that actual guideline implementation must be adapted to local survivor cohort profiles and healthcare system resources to improve the feasibility and sustainability of LTFU care.

Despite its strengths, a key limitation of this study is its retrospective single-centre design. Singapore is a small island nation with a multiethnic and multireligious population. The development of a national childhood cancer cohort with standardised surveillance guidelines, using its well-established cancer registry as a foundation, represents a more rigorous approach to LTFU programmes in this city-state. Additionally, psychological and psychosocial late effects were under-represented in this study. Although several international guidelines specify that all survivors are at risk of psychological and psychosocial problems, thus warranting routine screening during LTFU care,² these recommendations have not been consistently implemented in clinical practice, and this gap in practice is particularly evident in Asia.⁷ A recent multinational survey study⁴ found that only a third of surveyed institutions in Asia provide systematic screening for psychosocial problems. As the authors pointed out,

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the lack of standardised screening tools may be an important contributor to this gap. To date, countries and regions such as the US,⁸ India⁹ and Latin America¹⁰ have established standards of psychosocial care for paediatric cancer patients and validated assessment tools, such as the Psychosocial Assessment Tool¹¹ and ONPSIPED,¹⁰ aiming to identify at-risk survivors and provide personalised psychosocial interventions. Given Singapore's unique multireligious and multilingual context, similar efforts in this country could be directed towards validating psychosocial screening tools and developing culturally sensitive psychosocial interventions. Given the strength of its existing advocacy infrastructures, such as the VIVA Foundation for Children with Cancer, Singapore is in a key position to address the current gap in psychosocial care and provide capacity-building initiatives to strengthen survivorship efforts in Southeast Asia.

Currently, LTFU care implementation remains challenging in low- and middle-income countries (LMICs) across Asia.⁷ Regional collaboration may be a promising strategy for advancing equitable and sustainable survivorship care across Asia. In Europe, the PanCareSurFup project has built one of the largest childhood cancer cohorts, including over 83,000 survivors from 12 European countries.¹² Beyond generating robust evidence on late effects, this project has emphasised cross-national training and knowledge dissemination, thereby strengthening the capacities of clinicians and researchers throughout the region. In parallel with Lam Shang Leen et al.'s study,¹ the National Children's Medical Center-Shanghai LTFU Study Group has initiated a similar disease-specific LTFU care framework for late effect surveillance in 25 institutions in Hong Kong and mainland China, and is supported by the Hematology and Oncology Long-Term Follow-Up System for standardised treatment summaries and late effects documentation.¹³ Other national childhood cancer survivor cohorts and studies in Asia (e.g. Hong Kong, Japan, South Korea) have been published. Drawing on international experience, future efforts could leverage these existing national cohorts to create a multinational survivor cohort in Asia. Such an initiative could lay the groundwork for developing evidence-based and region-specific survivorship care guidelines for Asian childhood cancer survivors. The next step should also involve facilitating countries in the region, especially LMICs, to develop their own survivor cohorts, as well as the exploration of pooled national data registries. Such a valuable collaborative platform would enable studies on genetic, socioenvironmental and lifestyle risk factors for late effects among childhood cancer survivors and guide the implementation of targeted interventions in the region.

Ethics statement

Not applicable, as no study participants are involved.

Declaration

The authors declare there are no affiliations with or involvement in any organisation or entity with any financial interest in the subject matter or materials discussed in this manuscript.

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