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Editorial Comment

Medical surveillance of long-term survivors of childhood cancer

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Few could question the increasing importance of follow-up care for long-term survivors of childhood cancer, given the marked improvements in survival rates for paediatric and adolescent populations diagnosed with cancer. These rapid improvements occurred within a relatively short period of time, spanning only several decades. This has resulted in an increasing large cohort of at-risk patients who have a potential life expectancy that should extend well into old age and within a setting where complications of therapy may not become apparent until many years after cancer treatment. As a larger proportion of childhood cancer survivors enter adulthood, complications resulting from their cancer therapy may be exacerbated by organ dysfunction associated with ageing. Until a sufficient number of survivors treated with contemporary regimens enter middle age, we will not know the full long-term impact of therapeutic exposures during childhood. In recent publications from the US Childhood Cancer Survivor Study¹ and the Emma Children's Hospital/Academic Medical Centre in the Netherlands,² both reported that the majority (62% and 75%, respectively) of survivors had at least one chronic disease or adverse health condition with approximately 28–36% expected to have a serious or life-threatening physical health condition. It is noteworthy that both of these populations reflected cohorts of relatively young survivors with average ages of 24–26 years.

Aslett and colleagues have recently reported the results of a systematic literature review to describe selected topics relating to long-term follow-up of childhood cancer survivors.³ Specifically, they evaluated the literature addressing (1) the views of the cancer survivor and the health care professional on aspects of follow-up care; (2) various models of follow-up care, and (3) published guidelines and policies. This comprehensive and thoughtful review clearly emphasises the limited amount of empirical research that is available. Moreover, the available literature highlights the remarkable complexity of the issues that can or may influence optimal long-term clinical follow-up of this high-risk population. Adult survivors of childhood cancer are at risk for a variety of adverse health outcomes directly associated with their cancer treatment, which can be exacerbated by poor health behaviours, organ dysfunction associated with ageing, and other common co-morbid health conditions experienced during adulthood. Early detection and/or prevention or ameliorative interventions provide the opportunity to reduce cancer-related morbidity and mortality, and thus improve the overall quality of life of these long-term survivors.

Given the multiple and often related issues that influence the goal of providing optimum long-term follow-up care for childhood cancer survivors, individual programmes will need

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to tailor their approach based upon their available resources, in combination with known and potential barriers. Implementation of a comprehensive follow-up programme is resource intensive and can exceed the resources available through most health care systems. Thus, there needs to be a balance between available resources and the maximum benefit to the survivor population. The issue of cost:benefit has direct bearing on decisions regarding conduct of follow-up within a specialty clinic versus a primary care practice, or some combination of both. Barriers to providing access to and utilisation of follow-up services are many and include a broad range of issues such as health care systems/insurance, perceived value by both providers and survivors, physical and mental health status of the survivor, conditions associated with socioeconomic status and psychosocial function, as well as cultural values. Establishment and organisation of a follow-up programme for cancer survivors requires careful consideration of real or potential barriers to permit structure and process to maximise the delivered care to those at highest risk and need. The Nursing Committee of the US Children's Oncology Group is ready to release a remarkable reference resource that details the numerous components of long-term follow-up programmes. This document provides examples of organisation aspects and materials utilised by numerous programmes throughout the US and Canada.

As detailed in the recently published Aslett review,⁴ there is a limited, but growing number, of structured guidelines for recommended follow-up and evaluation of paediatric cancer survivors. While the process applied in formulating the recommendations vary with regard to reliance on the existing scientific evidence-base, there is a clear need for the conduct of scientifically rigorous evaluation of these recommendations to quantify the level of impact on survivor health. This represents a significant challenge, but an important undertaking. Within an environment of rapidly escalating health care costs, there will be increasing pressures to demonstrate the benefit of specific health care recommendations for long-term survivors of paediatric and adolescent cancers. Even if the recommended screening test may not be challenged, the timing of initiation and subsequent frequency of assessment will be subjected to scrutiny with regard to cost:benefit and in some instances risk:benefit. Beyond testing of interventions related to screening and early detection

guidelines, the challenge for the next generation of research investigations is to design and test prevention/early intervention strategies that can be directed to well-defined subpopulations at highest-risk for adverse health and quality of life outcomes. This class of prevention/intervention programme will require innovative methods and testing within a clinical trial setting to determine the efficacy of avoiding or reducing risk and maximising long-term health.

Also recently published in EJC was the summary of a gathering of a group of well-known academic investigators from the fields of paediatric oncology, epidemiology, nursing, and psychology, along with representatives of childhood cancer survivors and parents of childhood cancer patients.⁴ The stated aim of the gathering was to come to consensus on defining when the word 'cure' might be appropriately applied within the context of survivors of childhood cancer and to prepare a statement addressing childhood cancer survivors. Notwithstanding the criteria the group used for defining cure and the questionable view that risk should always be communicated 'in a positive light', the tenets put forth by this group are by-and-large rational and what most in the field would readily acknowledge as obvious. Nevertheless, the consensus statement validates issues of paramount importance to survivors and families who must deal with future uncertainties after successful treatment for childhood cancer.

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