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Commentary

Organisation of follow-up in paediatric oncology

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Better treatment over the last three decades has dramatically improved survival from paediatric cancer, with the result that an increasing number of patients now need long-term follow-up care. Currently, around 1 in 900 young adults are survivors of childhood cancer but they have or may develop sequelae of the malignancy or its therapy, threatening their future quality of life [1]. The main adverse outcomes are organ dysfunction, decreased fertility, neuropsychological problems and second neoplasms. There are several other difficulties such as obtaining employment and insurance, a diminished quality of life and early death [2–15]. Late effects clinics and programmes, now widely available [16,17], have a primary intent of monitoring for physical ‘late effects’, on the presumption that early detection will lead to less ultimate handicap. “Late effects” activities include attempts to provide survivors with relevant information regarding their medical history and possible complications, so that they can make appropriate health-related decisions and life choices [18–21]. Research is a separate, invaluable, second objective of long-term follow-up to document the late effects of previously used protocols in order to minimise toxicity and long-term damage.

Besides physical late effects, it is also important that late psychosocial effects are recognised because patients may benefit from appropriate intervention [10]. There appears to be no predominant single predictor of psychosocial outcome, although demographic background, differing treatments and complications, family resources, social circumstances, pre-existing coping strategies and supports and psychological issues during treatment [10,22] may each have an impact and must be considered in the development of support programmes. Survivors with ‘severe’ medical late effects have a lower self-esteem than those with late effects of a lesser degree and around one half of childhood cancer survivors experience such difficulties, including less effective socialisation and self-help skills and more variation in intellectual functioning [23]. Over half (59%) of these young people report psychiatric symptoms with a relatively high incidence of depression and of difficulty in resuming previous activities and lifestyle [2]. They may also complain of agitation, restlessness, social withdrawal and passivity [24], school-related problems and a concern for ongoing health status and medical needs [25]. In contrast, in other studies, survivors were found to achieve a ‘normal’ level of attainment in education and occupation [26,27], to be well adjusted [28,29] and not to experience unusual behavioural or emotional problems [30–32].

Individuals naturally have the right to information about their medical history, yet some people still believe that information of this sort can cause anxiety and may therefore ‘do more harm than good’ [20]. Parents, in particular, may be keen to ‘protect’ their child—even though the ‘child’ may now be a young adult—from the worry of possible late effects, often as a ‘coping strategy’. The balance of information provision is delicate and varies both from individual to individual and according to their stage of cognitive development. It is often necessary to provide information repeatedly over a number of years. This information must include a clear understanding of diagnosis, full treatment details and the potential for the development of late effects, including ‘second tumours’. Survivors informed in this way are better equipped to make appropriate decisions about crucial issues such as fertility, personal health surveillance and health-compromising behaviours such as smoking, physical activity, over-indulgence in alcohol and sunbathing [9,20,25,33]. It also ensures that survivors can pass on accurate information to future healthcare providers [21].

Although few studies have focused on this area, there is evidence that the quality of medical knowledge amongst survivors is, on the whole, poor and often inaccurate [20,21,34]. As a consequence, Oncology Units have introduced ‘educational’ items such as transcripts of medical interviews, written packages providing individualised information and educational seminars [20,35]. Information of this sort, specifically directed at

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long-term survivors, should be introduced universally and widely distributed.[1]

There are several reasons why some patients do not attend regular long-term follow-up clinics. Some survivors may not understand the need for follow-up and may therefore not perceive any personal benefit [9]. For example, those diagnosed at an early age may have no memory of their cancer experience and may not identify the history of cancer or its treatment as having any current or future implications. Others may feel that returning to the treatment Unit is too emotionally disturbing, so that any advantage is overridden. Yet others may feel that it is better to 'put the cancer experience behind them and move on' [20]. Prior to referral to a specialised 'late effects' service, it is therefore appropriate to explain the role of the clinic and its relevant support structures and identify survivors' baseline understanding of their disease and their perception of potential and actual psychosocial late effects. Procedures that provide survivors with the opportunity to identify and discuss the psychosocial issues, and gain access to members of the psychosocial team or community resources should all be discussed so that problems can be tackled early and effectively [35].

To summarise, long-term survivors usually benefit from the provision of appropriate long-term follow-up. Whilst recognising that the structure and atmosphere of 'late effects' clinics differs from Unit to Unit, each should embrace evidence-based protocols for the investigation, identification and management of the entire spectrum of 'late effects' [16,31] and introduce preventive strategies. After all, the purpose of cancer treatment these days is to cure with the least possible long-term toxicity ('cure at least cost') so that patients subsequently enjoy good health without the constant reminder of their previous illness and without becoming an unwarranted burden on the national health budget.

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[1] Editor's note: There are examples of excellent literature being available in Paediatric Oncology Units, but it is not always used.