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Original Research

Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork

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Abstract Evidence-based clinical practice guidelines are essential to ensure that childhood cancer survivors at risk of chronic health conditions receive effective long-term follow-up care. However, adult survivors of childhood cancer are not always engaged in recommended health promotion and follow-up practices, as many centres do not have a formal transition programme that prepares survivors and their families for successful transfer from child-centred to adult-oriented healthcare. The need for a specific pan-European guideline for the transition of care for childhood cancer survivors has been recognised. The first step is to define the concept of transition of care for survivors of childhood cancer based on existing evidence.

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1. The need for transition of care for childhood cancer survivors

In recent years, transition from child-centred to adult-oriented healthcare for childhood cancer survivors has become an increasingly important issue. Childhood cancer survivors are a growing population of individuals who are at high risk for premature morbidity and mortality due to their previous treatment and the cancer itself [1–4]. In an effort to reduce morbidity and mortality, several national and international initiatives have started to target childhood cancer survivors for engagement in health screening and surveillance programmes [5–9]. Unfortunately, although clinical practice guidelines recommend regular surveillance [10–14], only a minority of adult survivors are reported to receive regular risk-based follow-up [15–18]. Although most childhood cancer survivors receive regular long-term follow-up (LTFU) care in their paediatric centre during their childhood years, many centres do not have a specialised LTFU care for survivors who have reached adult age [17,18]. Even in centres that do have such a specialised adult service, patients often fail to transition from paediatric to adult care and are lost-to follow-up [18–20]. Many centres do not have a transition programme that prepares the survivors, their families and the future physicians for a successful transfer to the adult healthcare system, whether that is a specialised clinic or primary care [18–20].

2. The need for a specific transition of care guideline for childhood cancer survivors

Transition, independent of health status and age, takes place in our everyday lives, for example starting school, puberty, developing relationships, seeking employment. A major transition period is adolescence. It is a distinct phase of development characterised by a time of physical, sexual, psychological, emotional, cognitive and social changes and the establishment of self-identity. Decisions about lifestyle and vocation become important, and for many adolescents, relationships start to change in nature, range and quality. Adolescents form a distinct group, not needing the same degree of protection as children, but not yet ready for full independence [21].

The transition from paediatric to adult healthcare is an important part of this overall transition period. For most healthy adolescents, whose contact with health services is limited, the change from paediatric to adult healthcare is insignificant compared to other issues at that age and is usually not addressed. However, for an adolescent with special healthcare needs the transition to adult services can be a period of major stress and unfavourable consequences [22]. Young people with chronic conditions are vulnerable in terms of their emotional and behavioural development. Health service provision which fails to meet the needs of young people and their families at this time of significant change may result in deterioration in health or disengagement with services. Both of these outcomes can lead to adverse long-term consequences [22–25]. There are many factors that contribute to poor transition with one of the main reasons being inadequate preparation for transition, particularly if multidisciplinary care and guidance are required [26,27].

Adolescents with chronic health conditions usually transition to a specialist service that is the adult equivalent of the paediatric service they are leaving. This provides ongoing disease and transitional care. However, there is an important difference in the nature of transition for childhood cancer survivors. Although some childhood cancer survivors are generally healthy, many are in need of lifelong medical surveillance due to the increasing risk of developing late adverse effects during the course of their life. Furthermore, the potential late effects are very diverse and can include a whole range of different diseases and psychosocial problems, requiring specialist expertise in addition to that provided by the oncological speciality in which they were initially treated [1–4]. Therefore, transition is not simply a process of transfer to the adult equivalent of their specialised paediatric carer. Failure of transition and hence of appropriate surveillance for late effects may have potentially important medical consequences.

After successful completion of cancer treatment most survivors are transferred to a service that will provide risk-based LTFU care and surveillance. For young adults this service may not be based in the adult haematology/oncology department and in many cases it may be based in primary care, depending on the risk of late adverse effects. Wherever LTFU care is based, it needs to provide a wide variety of services, including general medical and psychosocial care, health promotion and facilitation of educational and vocational development for survivors and their families, and ideally support research to improve knowledge and care [10–14]. In order to better meet the needs of childhood cancer survivors, a specific guideline for the transition of their LTFU care is necessary.

The need for transition of care programmes for childhood cancer survivors has been recognised as an important aspect of survivorship care by the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare, www.pancare.eu) [28]. In 2008, PanCare was founded with the aspiration of ensuring that every European survivor of childhood and adolescent cancer receives optimal LTFU care. PanCareSurFup (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies [PCSF]; www.pancaresurfup.eu) is a European Union (EU)-funded collaborative project, the aims of