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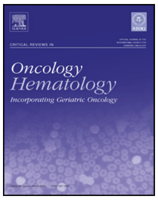

Review article

The impact of long-term follow-up care for childhood cancer survivors: A systematic review

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ABSTRACT

Objectives: Childhood cancer survivors are at risk of developing late treatment-related complications. In response, many hospitals worldwide have established follow-up clinics to monitor survivors as they age. However, there is limited evidence of the efficacy of these clinics in meeting the lifelong healthcare needs of survivors. In this review we collated evidence of the measurable impact of engagement in specialized survivorship care, on survivors' medical and psychosocial outcomes.
Design: We conducted a systematic review according to PRISMA guidelines, and assessed the quality of included studies using 'QualSyst'.
Data sources: We screened 641 abstracts in Medline, Embase and CINAHL, yielding 9 eligible articles (N = 5135 survivors).

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Eligibility criteria for selecting studies: Articles were eligible if: participants were diagnosed with cancer prior to the age of 21; participants were classified as 'survivors' of childhood or adolescent cancer, usually defined as 5 years from diagnosis or 2 years from the end of treatment; studies evaluated the impact of engagement in long term follow-up (LTFU) care on medical, psychosocial or other outcomes in pediatric cancer survivors.

Results: One article evaluated primary care physician-led follow-up and the remainder evaluated specialized survivorship clinics. Survivors attending follow-up care tended to demonstrate higher knowledge about their treatment and diagnosis (n = 2), and had more accurate late effects risk perception (n = 3). Attendees also engaged in increased more regular surveillance, had fewer emergency department visits/hospitalizations (n = 1), and more late effects detected (n = 3), than non-attendees.

Conclusions: There is a dearth of literature systematically evaluating the medical and psychosocial impact of follow-up care. Research suggests however, survivors engaged in follow-up care have better health and educational outcomes, highlighting the need for lifelong survivorship care and ongoing late effects education for survivors. Recalling survivors who become disengaged with follow-up care is also valuable, as their risk of treatment-related complications rises with age. Further systematic evaluation is urgently needed.

1. Introduction

Improvements in survival rates have resulted in growing concerns about childhood cancer survivors' (CCS) risk of developing treatment-related conditions (Oeffinger et al., 2006). Survivors are vulnerable to medical and psychosocial 'late effects' that are often associated with aging (Oeffinger et al., 2006; Signorelli et al., 2016). Three in every four survivors experience a late effect of their cancer treatment, 37% of which may be life threatening (Geenen et al., 2007). However, early intervention may reduce morbidity due to late effects (Schwartz, 1999). Numerous guidelines therefore recommend lifelong care for CCS, sparked by the landmark Institute of Medicine report on the organization of long term follow-up guidelines and clinics (Landier et al., 2004; Wallace et al., 2013; Hewitt et al., 2003).

The goal of follow-up care is to reduce the burden of late effects in CCS. Follow-up care is ideally comprehensive and interdisciplinary, focuses on preventing or managing late effects through surveillance, educates survivors on treatment-related complications, and encourages preventative lifestyle behaviors (Hollen and Hobbie, 1995). Risk-based anticipatory care received at long term follow-up clinics is recommended to reduce morbidities and mortality associated with treatment for pediatric cancer (Grossi, 1998). Engagement in follow-up is intended to foster ongoing education, screening, early detection, and where possible prevention, of late complications and second malignancies, facilitating early intervention when complications arise, and ultimately leading to improved medical and psychosocial outcomes in the long-term (Marina, 1997).

Follow-up recommendations may differ for survivors, based on their diagnosis, and treatment type(s) and intensity (Edgar et al., 2013). Higher risk survivors often continue receiving their follow-up care through specialized Long Term Follow-Up (LTFU) clinics, usually at their treating hospital. Medium and low-risk survivors may be referred to their Primary Care Physician (PCP) for a shared-care (joint participation from PCPs and specialists) or PCP-led model respectively. With demand on pediatric oncology services surpassing supply, other survivors are formally transitioned from their pediatric center to an adult service (primary care or hospital-based), often depending on how they are risk-stratified (Henderson et al., 2010).

Given the strong calls to offer LTFU care to CCS, increasing resources are being allocated worldwide to guideline and resource development (Henderson et al., 2010). Yet, up to 68.5% of long term survivors do not engage in any cancer related follow-up care (Nathan et al., 2008), and there are several patient-, provider- and system-related barriers to care (Oeffinger, 2003). In particular, young adult survivors of childhood cancer often become disengaged from follow-up following the transition from pediatric to adult healthcare (Henderson et al., 2010; Freyer, 2010). Accordingly, interventions to re-engage CCS into long term follow-up are being developed (Edgar et al., 2012). However the efficacy and cost-effectiveness of such care is yet to be established (Oeffinger and McCabe, 2006). A review of the evidence summarizing the impact of receiving long term follow-up care in CCS is therefore overdue (Tonorezos and Oeffinger, 2015).

This systematic review aimed to evaluate the medical and psychosocial impact of attending a long term follow-up clinic or receiving specialized cancer care in the childhood cancer survivor population. Specifically, the review aimed to answer the following research questions:

1) What is the impact on CCS of attending LTFU, in comparison to not attending?
2) Is there a difference in the impact of LTFU care received by survivors at specialized survivorship clinics or centers, as compared to care in the primary care setting?

2. Methods

2.1. Data sources and searches

This systematic review was guided by Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) procedures (Edgar et al., 2012).We searched three electronic databases (Medline, Embase, and CINAHL), Google Scholar and two grey literature databases (Trove and Open Grey), up to June 2016, and limited to English and human studies (See Supplemental Table 1 for the search algorithm).

2.2. Inclusion criteria

Articles were eligible if:

1) Participants were diagnosed with cancer prior to the age of 21
2) Participants were classified as 'survivors' of childhood or adolescent cancer, usually defined as 5 years from diagnosis or 2 years from the end of treatment
3) Studies evaluated the impact of engagement in LTFU care on medical, psychosocial or other outcomes in pediatric cancer survivors