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## Review

## Patterns and drivers of health care use in long-term childhood cancer survivors: A systematic review

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## ABSTRACT

**Background:** Childhood cancer survival is increasing. But cancer and treatment late-effects can lead to ongoing health care use. We summarised the literature on the patterns and drivers of health care use among childhood cancer survivors.**Method:** Pubmed, Embase and Medline were searched for studies reporting health care use in childhood cancer survivors.**Results:** We included 22 studies, covering 88787 experiences of health care use. The proportion of survivors using follow-up care, physician visits, specialist visits, hospitalisations, dental care and screening services varied (36.4%–88.8%). Participation in screening was below recommendations (11.5%–81%). Drivers of increased health care use included higher income, private health insurance, attending follow-up care, chronic health conditions, prior radiotherapy, being female and older age.**Conclusion:** Sociodemographic and clinical factors result in differences in health care use. Future research could investigate whether such use is appropriate and how survivors might be engaged to receive care appropriate to manage their needs.

## 1. Introduction

Improvements in cancer therapy have led to 5 year survival rates of children diagnosed with cancer exceeding 80% (Howlader et al., 2016). However, as a result of their cancer and its treatment, long-term childhood cancer survivors (CCS) are at higher risk of developing psychosocial problems, organ dysfunction, secondary cancers and comorbidities compared to the general population (Mertens et al., 2001). The risk of late effects increases over time. It is estimated that 73% of CCS will develop at least one chronic physical health condition by age 40 and 42% will develop a severe, life-threatening or disabling condition, or die from a chronic condition (Oeffinger et al., 2006). The risk of late effects is not only affected by the primary cancer diagnosis, but is also influenced by the type of therapy received (Sklar, 1999a; Oeffinger and Hudson, 2004). For example, children who received radiation therapy have a higher risk of developing growth impairments, intellectual disabilities and organ dysfunction (Marina, 1997). The increased survival rate, combined with increased risk of comorbidities,

emphasizes the importance of long-term follow-up for CCS.

During long-term follow-up, CCS use different health care services including both specialist and screening services, depending on their need and history (Nathan et al., 2008). Visits to health care services as part of survivors' long-term follow-up are essential to detect comorbidities and cancer recurrence (Hewitt et al., 2003). These appointments also provide an opportunity for CCS to develop their awareness about their risk of recurrence, comorbidities and behavioural strategies to reduce the risk of late effects (e.g. healthy diet and exercise) (Pollack et al., 2005).

While there is the potential for survivors to benefit from regularly engaging with health care services (Signorelli et al., 2017), not all survivors are actively engaged with health care services or in long-term follow-up. Up to three quarters of survivors are not engaged in cancer-related follow-up care (Casillas et al., 2015; Vetsch et al., 2017; Miller et al., 2017; Wilson et al., 2009). The patterns and drivers of health care use (HCU) among CCS have been investigated in a number of studies (Nathan et al., 2008; Maeda et al., 2010; Oeffinger et al., 2004; Steele

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et al., 2013; Johnson et al., 2004). Yet findings vary on the principal drivers of HCU among CCS, ranging from socio-demographic factors, such as age, gender and income, to clinical characteristics such as the time since diagnosis and the type of treatment received (Nathan et al., 2008; Oeffinger et al., 2004; Steele et al., 2013; Johnson et al., 2004).

To date, there has not been a systematic review published on the patterns and drivers of HCU among long-term CCS. Therefore, we undertook a systematic review to 1) evaluate and summarise the literature on HCU among CCS; and 2) identify clinical and demographic factors influencing the use of health care among CCS.

## 2. Method

### 2.1. Literature search and study selection

We defined HCU as any hospital visits, long-term follow-up clinic visits, use of pharmaceuticals, physician visits dental care visits and visits to a care provider for health screening procedures. The use of health screening procedures (e.g. cancer, cardiac and bone health) are also considered separately as these are of particular interest in the monitoring of the ongoing health of CCS. Studies reporting factors affecting HCU, and measures of HCU, were identified by searching Pubmed, Embase and Medline on September 12, 2016. No time limits were applied to the search. The search terms shown in [Text Box 1](#) were applied across all three databases. We also conducted a manual search of the reference lists of included papers for potentially relevant studies not identified in our database search. The procedure used for the literature search is outlined in [Fig. 1](#).

### 2.2. Screening and data extraction

Two reviewers (JB, CS) assessed the citations retrieved, and potentially eligible full text versions, for inclusion. Reviewer one (JB) extracted data on HCU using the categories as reported by the included studies, and factors influencing that HCU in each eligible study. To check the consistency of data extraction, reviewer two (CS) extracted data from a random sample of 10% of the included studies. Any discrepancies between the reviewers were discussed until a consensus was reached.

### 2.3. Inclusion and exclusion criteria

Publications were included if they reported quantitative data on HCU by paediatric (under the age of 21) cancer survivors (at least five years from diagnosis). Consequently, publications were excluded if they met one of the following criteria: (i) reported on patients who were diagnosed with cancer after 21 years of age; (ii) patients were less than 5 years from diagnosis; (iii) were published in a language other than

English; or (iv) did not report quantitative data on HCU in survivors of a paediatric cancer (including abstracts of conferences, letters, notes, non-systematic reviews or opinion pieces, or papers reporting data from already included studies). As our systematic review is focused on the drivers of HCU, studies were considered eligible for review of those driving factors if they reported the results of multivariate analyses exploring the factors associated with health care use. Studies reporting results for univariate analyses only were retained for descriptive purposes but excluded from the systematic review of factors associated with HCU due to the inherent uncertainties associated with univariate analyses. The results of the review of citations are provided in [Fig. 1](#).

### 2.4. Quality assessment

To facilitate the interpretation of the combined findings from the included studies, we assessed their quality using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers developed by Kmet et al. (LRC, 2004). This scoring tool consists of 14 questions covering the quality of study design, methods, outcomes and measurements. Study quality was scored according to the degree to which each of the quality criteria were met (“yes” = 2, “partial” = 1, “no” = 0 and “n/a” for questions not applicable). Summing over the 14 possible quality criteria, the maximum possible quality score for any given study was 28. For each included study, quality was assessed by two reviewers (JB, CS) independently and discrepancies were discussed until a consensus was reached. An average quality score was estimated for those studies reporting the results of multivariate analyses which formed the basis of the systematic review.

## 3. Results

We identified 314 unique publications from the electronic search. A further 14 studies were identified through the manual search. After applying the inclusion and exclusion criteria to these 328 citations, 41 remained for full text review of which 22 were retained following exclusions. Of those 22 publications, 17 reported results for multivariate analyses and were deemed eligible for inclusion in the systematic review, with five reporting results from univariate analyses only.

A detailed summary of the 17 studies included in the systematic review is provided in [Table 1](#); information about the five univariate studies is provided in [Table 2](#). The sample size across all 22 studies ranged from 96 to 10366, with a total of 88787 survivor experiences of care represented across the included studies. The average participation rate (i.e. the proportion of individuals invited who participated in the data collection process in each of the studies respectively) across the studies was just under 62%. Four studies used a single centre design (Johnson et al., 2004; Ford et al., 2013; Klosky et al., 2008; Stevens et al., 1998); the other 18 were multicentre study designs (Casillas

### Text Box 1

PubMed Search Strategy.

```
Neoplasms
AND
(Adolescent OR child OR young adult)
AND
(Survivors)
(AND)
(Childhood cancer survivor OR pediatric cancer survivor OR paediatric OR adult cancer survivor OR pediatric malignancy survivor OR
paediatric malignancy survivor OR long term cancer survivors)
AND
(Health service utilisation OR health service utilization OR health service use OR long term follow up OR medical care)
AND limits: (English language) AND (humans)
Remove duplicates
```

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