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# “Forewarned and forearmed”: Long-term childhood cancer survivors’ and parents’ information needs and implications for survivorship models of care

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### ABSTRACT

**Objective:** This mixed-method study assessed 1) survivors' and parents' information needs; and 2) associations between unmet information needs and clinical and socio-demographic characteristics.

**Methods:** Stage 1: CCS and parents of CCS, >5years post-diagnosis completed a questionnaire on information needs, overall health and perceived risk. Predictors for unmet information needs were assessed by multivariable regression. Stage 2: participants were interviewed in-depth on these topics.

**Results:** Questionnaires were completed by 485 participants comprising 322 survivors (mean age: 26.7years, SD=7.9; time since diagnosis: 19.7years, SD=8.8) and 163 parents (child age: 12.9years, SD=2.4; time since diagnosis: 9.7years, SD=2.3), and complemented by 70 interviews. Survivors reported unmet information needs about late effects (57.5%) and parents for fertility issues (62.5%). Survivors had more unmet needs for medical information whereas parents had significantly more regarding sexual issues and lifestyle. Being a parent ( $p=0.001$ ), dissatisfaction with follow-up care ( $p=0.003$ ), lower overall health ( $p=0.014$ ), higher perceived risk of late effects ( $p<0.001$ ), and greater anxiety/depression ( $p<0.001$ ) were significantly associated with more unmet needs.

**Conclusion:** Unmet information needs were common for survivors and parents of CCS.

**Practice implications:** Future efforts towards tailoring information on potential late effects, healthy lifestyles and follow-up care may help to address unmet information needs.

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## 1. Introduction

Childhood cancer diagnosis and treatment are traumatic experiences for patients and their families [1]. During treatment, the child and parents have to cope with a lot of new nontrivial medical information to make informed decisions, continuing in the years post-treatment and into survivorship. Childhood cancer survivors (CCS) are at high risk of developing late effects decades after treatment has ended, due to the cancer and/or treatment they received as a child [2]. Lifelong, risk adapted follow-up care is therefore recommended [3,4]. Optimal participation in health care including follow-up necessitates having appropriate information, [5,6] and access to more information leads to greater involvement

in treatment-related decision-making [7] and possibly awareness of late effects [8–10].

Among support needs reported by childhood cancer patients, information needs are commonly unmet, [11,12] and can vary over time. Shortly after treatment parents and survivors report wanting information on fertility and about the challenges of being off treatment [13]. Many years after treatment, parents and survivors report unmet information needs particularly for medical topics such as late effects and follow-up care [12,14,15]. Two long-term Swiss studies showed over 60% of survivors and more than 50% of parents had information needs about follow-up care or late effects more than a decade after diagnosis [14,15]. In the Netherlands, even after visiting a late effects outpatient clinic, almost 30% of survivors/parents had unanswered questions mainly regarding recognizing late effects [16].

Adult cancer survivors with lower information needs, and fewer information barriers, report better health-related quality of life (QoL) and less anxiety and depression [17,18]. Clinical and socio-demographic factors associated with increased information needs in CCS and parents have rarely been studied. There is some evidence that high information needs are associated with lower QoL, and higher psychological distress [15] and cancer related anxiety/fear [12]. Survivors who are female, younger at diagnosis, and of poor physical health more frequently report unmet information needs [19]. In parents of CCS, high information needs are reported by parents with a migration background and those with greater concerns about cancer recurrence [14]. However, some CCS feel stressed and overwhelmed with the amount of information they have received and report no need for additional information [20]. Some parents also report resisting further information for fear of its potentially negative impact [21]. Therefore, it is important to find a balance of delivering the right amount of information at the right time [22].

No studies have previously investigated the information needs and possible correlates of long-term CCS and their parents in Australia and New Zealand. Meeting information needs and detecting those at highest risk is important to ensure engagement in follow-up care. This mixed-method study investigated information needs of long-term survivors and parents of CCS in a binational cohort where health care (including follow-up care) is publically available, but not consistently accessed. We aimed to 1) assess information needs of survivors and parents of CCS; and 2) investigate associations between unmet information needs and clinical and socio-demographic characteristics of survivors and parents.

## 2. Methods

This is a two-stage mixed-methods study. In stage 1, questionnaires were distributed to CCS and parents of CCS. In the second stage we conducted in-depth telephone interviews with participants who completed the questionnaire and indicated consent to an interview in the questionnaire. Quantitative data from the questionnaire was used to inform qualitative data from interviews. The qualitative findings are then used to explain the quantitative results [23].

### 2.1. Participants

Eligible survivors were diagnosed with any form of cancer before age 16 years, >5 years post-diagnosis, had completed active treatment, were proficient in English and were alive and in remission. For survivors below 16 years, we invited parents to participate on behalf of their child. One questionnaire was completed per survivor or parent. Packages sent to survivors

between 16 and 18 years included two letters, one each addressed to the parent(s) and the survivor, and the decision was left to the family as to whether who completed the questionnaire. Survivors over 18 years of age completed their own questionnaires.

### 2.2. Procedure

Participants were identified through medical records of each hospital. We also advertised the study through national media to reach CCS who were dis-engaged from their treating hospital or follow-up clinic. We mailed questionnaires to CCS and parents of CCS treated at eight paediatric hospitals in Australia and New Zealand. Potential participants were posted an invitation letter from a lead clinician at the hospital at which they were treated, consent form, questionnaire and reply-paid envelope. Questionnaires could also be completed online. Non-respondents were telephoned after four weeks up to four times, or after surveys were resent twice at the participant's request, whichever came first.

Semi-structured telephone interviews were administered by a clinical psychologist and piloted. The interviews were recorded and transcribed verbatim.

The study was approved by the relevant ethics authority for all participating hospitals and was endorsed by the Australian and New Zealand Children's Haematology Oncology Group.

### 2.3. Measures

The questionnaire was designed by an expert committee and piloted with five survivors and five parents. It assessed participants' information needs (met or unmet); and demographic and clinical characteristics (Table 1). All responses were anonymous.

### 2.4. Outcome

*Information needs:* We assessed information needs related to medical topics, psychosocial needs, and lifestyle behaviors using a purpose designed 22-item questionnaire. Response options were: 1 = 'not needed', 2 = 'needed but not received', 3 = 'needed and received some' and 4 = 'needed and received enough'. For the analysis we dichotomized the variable into *total information needs*: No needs = answer 1, yes = answer 2, 3 or 4; and into *unmet information needs*: No = answer 1 or 4, and yes = answer 2 or 3.

### 2.5. Explanatory variables assessed by questionnaire

#### 2.5.1. Socio-demographic information

We assessed survivor's age, survivor's sex, relationship to survivors, survivors' and parents' ethnic background, survivors' and parents' place of residence, survivors' and parents' education level (no post-school qualification/post-school qualification: apprenticeship, TAFE [vocational tertiary education] certificate/diploma, college, university degree, post-graduate degree) and survivors' and parents' employment status, survivors' and parents' income and having private health insurance (Table 1).

#### 2.5.2. Medical characteristics (self-reported)

Attendance at long-term follow-up (LTFU) clinic (yes/no), receipt of treatment summary and/or survivorship care plan (SCP, 0 = none received, 1 = treatment summary only, 2 = treatment summary/SCP), date of diagnosis, date of treatment completion, treatment received and whether their cancer had relapsed, were self-reported. Participants reported their, or their child's diagnosis, which we categorized into leukemia, lymphoma, brain tumor and 'other', according to International classification of childhood cancer (ICCC-3) [24] for statistical analysis.

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