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# The Lived Experience of Childhood Cancer Survivors and Their Parents: A Multi-National Study of Access to Survivorship Care and Information and Support Needs

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## ABSTRACT

**Introduction:** Lifelong follow-up care for childhood cancer survivors (CCS) is recommended and ideally involves both medical and psychosocial care. It is important for CCS and their families to be adequately informed about what to expect after cancer treatment completion to ensure they receive appropriate care. This study aimed to describe patterns of access to survivorship care among a multi-national sample, as well as examine unmet information and support needs, for CCS and their parents.

**Method:** An online survey, developed by pediatric psycho-oncology experts and people with lived experience of pediatric cancer, was distributed by the World Health Organization. This study presents a subanalysis from these data.

**Results:** Participants included 102 parents of CCS (94 females, mean age 45 years, mean time since child's diagnosis 9 years), and 43 CCS (28 females, mean age 31 years, mean time since diagnosis 21 years) from 17 countries. Thirty-five percent of CCS (13/37) were not accessing survivorship care. Most parents (95%; 97/102) and CCS (76%; 31/41) reported a desire for discussion of emotional impacts following cancer treatment completion; however, this did not occur for 69% (70/102) of parents and 46% (19/41) of CCS. Additionally, 92% (93/102) of parents and 83% (33/41) of CCS reported an unmet need for more information about what to expect after cancer treatment. Most CCS (54%; 22/41) reported feeling "somewhat—not at all" supported by healthcare professionals in the period after cancer treatment.

**Conclusion:** Discussions regarding emotional well-being and ongoing needs post treatment are lacking in cancer survivorship care worldwide.

**Abbreviations:** CCS, childhood cancer survivors; HCP, healthcare provider; HIC, high-income country; LMIC, low middle-income country.

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## 1 | Introduction

A diagnosis of childhood cancer marks the beginning of a lifelong journey for the child, their family, and other loved ones. Fortunately, due to advances in diagnostic and medical sciences, survival is now the most probable outcome for many cancers, with 5-year overall survival rates climbing to above 80% in high-income countries (HIC) [1, 2]. However, curative treatment does not mark the end of the cancer experience. There is increasing evidence of significant long-term impacts on physical and psychosocial functioning that necessitate ongoing survivorship care, ideally beginning prior to, or at the end of cancer treatment, and continuing across the lifespan [3]. Survivorship care should be multidisciplinary, to address both medical and psychosocial late effects [4–6].

Importantly, late effects of childhood cancer and its treatment may develop years or decades post treatment [7], and include a wide range of conditions from pulmonary, endocrine, or cardiac conditions, to cognitive dysfunction, infertility, second cancers, and psychosocial concerns (such as fear of recurrence, depression, and anxiety) [8–10]. By middle-age, it is estimated that 95% of childhood cancer survivors (CCS) will have experienced a chronic health condition, and 80% a serious or life-threatening chronic condition [11]. Given the extensive latency periods and the wide range of potential health conditions, coupled with the high likelihood of their occurrence, there is a necessity for proactive and ongoing dialog between clinicians and CCS post treatment. However, the availability of medical and psychosocial risk education in the clinical settings, and its effectiveness, is not well understood [12]. While psychosocial support is acknowledged by most medical teams as necessary, more than a quarter of healthcare providers (HCPs) report that their psychological care for CCS is not ideal [13]. In turn, it is well documented that the majority of CCS do not access appropriate psychological care to manage mental health problems including post-traumatic stress disorder, depression, and anxiety [14].

Furthermore, despite several international guidelines recommending that CCS should receive regular survivorship care, research suggests that CCS are suboptimally engaging with such services [15]. Known barriers to engaging with survivorship care include lack of education regarding the importance of survivorship care, lack of access, and prohibitive costs, impacting survivors from both high- and low middle-income countries (HIC and LMIC) [16–18]. In HIC, there exist high rates of unmet information needs in CCS [19–22], with parents often reporting unmet information needs at a similar rate to CCS, albeit on different subjects [23]. CCS often report that clinicians are providing information to a parent during treatment, but transference of this information to the child at an age-appropriate time is not always achieved [24].

In LMIC, there is a dearth of evidence regarding the unmet needs of CCS and parents. A recent review of the unmet needs of relatives of childhood cancer patients and survivors identified only two studies from LMICs [24], offering limited data on mothers and none on the survivorship period or the lived experience of CCS [25, 26]. A report of unmet supportive care needs across the Asia-Pacific region reported that survivors

in LMIC experience a significantly higher number of unmet needs, specifically psychosocial and comprehensive cancer care, compared to survivors in HIC in the region [27].

Therefore, this study aimed to understand, from a multi-national perspective, (i) whether CCS and their families are accessing survivorship care and whether they perceive this as important; and (ii) whether their late effects information needs and emotional support needs are being met in the period after cancer treatment completion, namely, the survivorship period.

## 2 | Method

This dataset is part of a wider World Health Organization (WHO) observational, cross-sectional study aiming to capture the lived experience of people affected by cancer internationally, from both HIC and LMICs [28, 29]. The survey was developed by an international multidisciplinary team of experts, with researchers and people with lived experience of childhood cancer, from the United States, Europe, Africa, and Australia. Using the WHO Quality of Life framework, the survey instrument included both purpose-built items and validated instruments [30]. A detailed description of the survey items used for analysis in this dataset can be found in Tables 1 and 2. The online survey was distributed internationally by the WHO via the LimeSurvey software platform. The study used convenience sampling, and snowballing through professional networks and organizations related to cancer or cancer survivorship. The survey was made available on the WHO website, announced at the World Cancer Congress in Geneva, Switzerland, in 2022, and made available in English, French, and Spanish. HCPs were not directly approached for recruitment.

Participants met inclusion criteria if they: (i) were currently over 18 years of age; (ii) had been diagnosed with cancer in childhood (<18 years); and (iii) had completed cancer treatment. Or, if they were the parent of a person (currently any age) who had previously been diagnosed with a childhood cancer and had completed treatment or had died.

All participants provided information on age, gender, language spoken at home, time since final cancer treatment, and country of residence.

### 2.1 | Data Analysis

All data were analyzed in STATA version 16. Descriptive statistics were reported as percentages and proportions where additional clarity is required. As all survey items were nominal or ordinal, Chi-square tests of independence were used to examine bivariate relationships between items.

## 3 | Results

Participants were 102 parents of CCS (92% female, mean age 45 years, mean time since child cancer diagnosis 9 years), and 43 CCS (65% female, mean age 36 years, mean time since diagnosis 21 years). Participants represented 17 countries, ranging on the World Bank income classification from low-middle to high (see

TABLE 1 | Childhood cancer survivors questionnaire items.

Question	Response options
<b>Access to and perceptions of survivorship care</b>	
Do you currently experience any long-term side effects of cancer treatment?	No, I do not experience any long-term side effects Yes, I do experience some or many long-term side effects
Since you finished your cancer treatment, have you ever seen a doctor or nurse who specializes in providing cancer-related follow-up care? (i.e., a doctor or nurse who provides cancer survivorship care)	No Yes
Below are some opinions and feelings that cancer survivors have expressed about cancer-related follow-up care. Please mark whether you agree or disagree with the following statements:	Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree
1. Regular cancer follow-up visits give me a feeling of security or safety.	
2. I would worry more about my cancer if there were no follow-up visits.	
3. I believe regular follow-up care will help me live better after cancer.	
How supported by health professionals did you feel AFTER your cancer treatment?	Not at all Somewhat Very
<b>HCP communication, information, and support needs</b>	
Overall, since you finished your cancer treatment, how often did the health professionals who care for you:	Never Sometimes Usually Always
1. Listen carefully to you?	
2. Explain things in a way you could understand?	
3. Show respect for what you had to say?	
4. Encourage you to ask all the cancer-related questions you had?	
5. Make sure that you understood all the information they gave you?	
6. Spend enough time with you?	
7. Give you as much cancer-related information as you wanted?	
Has a health professional ever discussed with you what late or long-term side effects of cancer treatment you may experience over time?	I don't know No, I was not told Yes, a family member was told, or I was told
At any time since you were first diagnosed with cancer, were you ever told by a health professional that you needed regular follow-up/survivorship care and monitoring after your cancer treatments were over?	Unsure No, I was not told Yes, someone in my family was told, or I was told
Did you want more information about what to expect when you/your family member completed cancer treatment?	Not at all Somewhat I don't know For the most part Definitely
Would you have wanted any health professionals to talk with you about how you might feel emotionally after you finished your cancer treatment?	Not at all Somewhat For the most part Definitely
Did any health professionals talk with you about how you might feel emotionally after you finished your cancer treatment?	Not at all Somewhat For the most part Definitely

(Continues)

TABLE 1 | (Continued)

Question	Response options
Since you or your family member was diagnosed with cancer, have you ever seen a mental health professional (e.g., psychologist/psychiatrist/counsellor) for support related to your cancer experience?	No Yes
Do you feel your psychological support needs are currently being met?	No Yes

TABLE 2 | Parent questionnaire items.

Question	Response options
<b>Access to and perceptions of survivorship care</b>	
How supported by health professionals did you feel AFTER your family member completed cancer treatment?	Not at all Somewhat Very
Overall, how would you rate the quality of care your family member received after they finished their cancer treatment?	Poor Fair Good Very good Excellent
<b>Access to and perceptions of survivorship care</b>	
Has a health professional ever discussed what late or long-term side effects of cancer treatment your family member may experience over time?	Unsure No, I was not told Yes, my family member with cancer, or I was told
At any time since your family member was first diagnosed with cancer, were you ever told by a health professional that they needed regular follow-up/survivorship care and monitoring after their cancer treatments were over?	Unsure No, I was not told Yes, my family member with cancer, or I was told
Did you want more information about what to expect when your family member completed cancer treatment?	Not at all Somewhat I don't know For the most part Definitely
Would you have wanted any health professionals to talk with you about how you might feel emotionally after your family member finished their cancer treatment?	Not at all Somewhat I don't know For the most part Definitely
Did any health professionals talk with you about how you might feel emotionally after your family member completed cancer treatment?	Not at all Somewhat I don't know For the most part Definitely

Table 3). English was the first language for 93% of parents and 43% of CCS.

### 3.1 | Access to and Perceptions of Survivorship Care

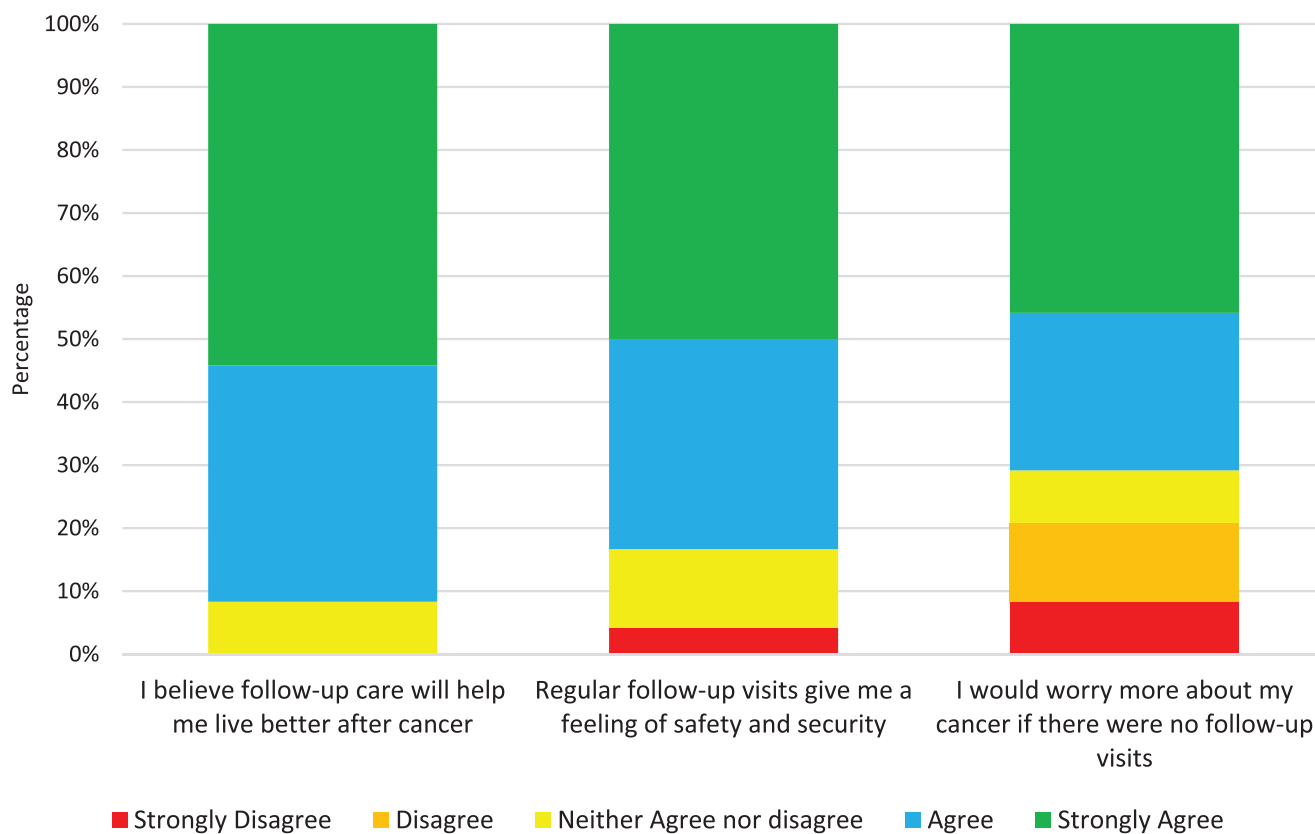
Sixty-eight percent of CCS ( $N = 27/40$ ) reported currently experiencing late effects. Most (65%) had seen a doctor or nurse

who specializes in providing survivorship care. To note, there was no relationship between those who experienced late effects and those who saw an HCP for survivorship care ( $\chi^2 = 3.31$ ,  $p = 0.19$ ). Among CCS who had seen an HCP for survivorship care, reported survivorship care helped them live better after cancer ( $N = 22/24$ ), survivorship care gave them a feeling of safety or security ( $N = 20/24$ ), and that they would worry more about their cancer without survivorship care ( $N = 17/24$ ) (see Figure 1).

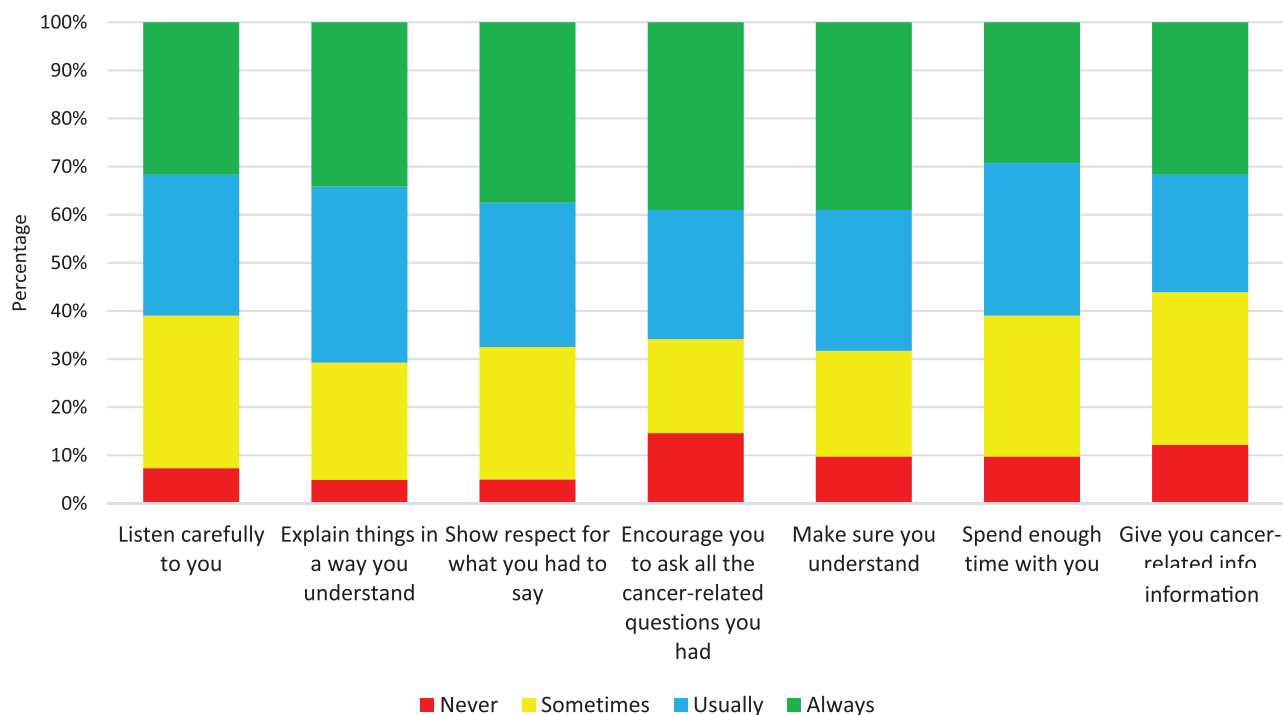
**TABLE 3** | Number of participants represented by country.

Country	CCS	Parent	World Bank income classification
Australia	2	6	High
Belgium	1	0	High
Canada	0	9	High
Ecuador	1	0	Upper middle
Egypt	0	1	Lower middle
Germany	5	0	High
India	11	4	Lower middle
Ireland	2	1	High
Luxembourg	1	0	High
Oman	1	0	High
Romania	1	0	High
Serbia	0	1	Upper middle
Slovenia	1	0	High
Spain	1	0	High
UK	0	1	High
USA	15	79	High
Uruguay	1	0	High
<i>Total</i>	43	102	

Abbreviations: CCS, childhood cancer survivors; UK, the United Kingdom; US, the United States of America.



**FIGURE 1** | Childhood cancer survivors' (CCS) perceptions of follow-up care ( $n = 24$ ).



**FIGURE 2** | Childhood cancer survivors' (CCS) perceptions on the supportive skills of their HCPs.

Across the CCS cohort, 54% (22/41) reported they felt “somewhat” or “not at all” supported by health professionals after their cancer treatment. Parents also provided a response to this item, and similarly, most (54%) indicated feeling “somewhat” or “not at all” supported after their child completed cancer treatment. Although many parents did not feel supported, most (79%) still felt that the quality of their child’s survivorship care was good, very good, or excellent.

## 3.2 | Information and Support Needs

### 3.2.1 | HCP Communication and Patient-Centered Care Skills

CCS ( $n = 41$ ) were asked to rate HCPs’ communication and patient-centered care skills, such as explaining information clearly, seeking questions, listening, showing respect, and providing sufficient time. While most CCS reported HCPs “usually” or “always” demonstrated these skills, it should be noted that many CCS felt HCPs “never” or only “sometimes” demonstrated these skills. For example, 44% reported that HCPs “never” or only “sometimes” provided cancer-related information, and 39% of CCS reported that HCPs “never” or “sometimes” listened carefully to survivors (see Figure 2).

### 3.2.2 | Information Needs

Some CCS (35%, 14/40) reported that HCPs had never discussed their personal risk of developing late effects with either themselves or their family, and 23% reported that HCPs had never discussed that they needed regular survivorship care after their treatment was completed with either themselves or their

family. In contrast, only 5% of parents reported that HCPs had never discussed their child’s personal risk of developing late effects with either themselves or their family, and 2% reported that HCPs had never discussed that their child needed regular survivorship care after treatment was completed with either themselves or their family. CCS (83%) and parents (92%) reported wanting more information about what to expect when they or their child completed cancer treatment. The association between CCS’ information needs and accessing survivorship care was not statistically significant ( $\chi^2 = 6.72, p = 0.15$ ).

Most CCS (75%) and parents (95%) reported wanting an HCP to discuss how they might feel emotionally after treatment completion; however, this did not occur for almost half of CCS (46%) and most parents (69%). Many CCS (42%) had never seen a mental health professional for support since their cancer diagnosis, and 37% reported their psychological support needs were not currently being met.

## 4 | Discussion

This study, one of the first of its kind to be disseminated internationally, highlights significant gaps in survivorship care. Our findings indicate that despite the known prevalence of late effects and the importance of follow-up care, a substantial number of CCS do not access these services and remain uninformed about potential long-term outcomes.

Our findings align with previous research indicating that CCS often experience significant unmet needs in both information and emotional support domains. Prior studies in HICs have similarly identified a lack of education regarding the importance of survivorship care and the presence of unmet information needs

among CCS and their families [19, 21, 23]. However, our study extends this knowledge to a more diverse, multi-national sample, including some participants from LMICs, where data on this topic are extremely limited [18]. This broader perspective suggests a universal challenge in the delivery of survivorship care.

Importantly, this study found a high percentage of parents (95%) and CCS (76%) expressed a desire for discussions about the emotional impact of the cancer experience, yet 69% and 46%, respectively, did not have these conversations with their clinical team. In addition to lack of clinician-led emotional discussions, and poor communication skills (e.g., 39% of CCS felt HCPs “never” or only “sometimes” listened carefully to survivors), a substantial proportion of CCS had never seen a mental health professional since their cancer diagnosis. This further underscores the lack of integration of psychosocial care into survivorship programs. This is problematic given that CCS are known to report unmet needs for psychosocial support, they are at increased risk of developing psychological late effects, and over 40% report experiencing fear of cancer recurrence [9, 31, 32]. The current findings suggest a critical need to re-evaluate and enhance the supportive skills of healthcare professionals, particularly in the context of providing comprehensive emotional and psychological care.

Exploratory findings from this study suggest a difference in the perceived support and information parents and CCS receive. While almost all parents reported they had had discussions with their child’s clinician about potential late effects and the need for ongoing follow-up care, a considerable number of CCS indicated they had not received the same level of information or support. This discrepancy highlights a potential gap in communication and information transfer between HCPs, parents, and CCS. It suggests that while parents may feel well-supported and informed, this information is not always adequately relayed or tailored to CCS, who may have different or additional needs for information as they age. This finding underscores the importance of long-term access to survivorship care and, ensuring that CCS are empowered with the knowledge and resources to manage their own health and well-being effectively when they mature sufficiently to become independent of their parents.

Addressing this communication gap could improve CCS’ engagement with survivorship care and enhance their overall quality of life. The *Engage* childhood cancer survivorship program is an example of effective nurse-led, comprehensive review of young people’s health concerns in the survivorship period and personalized education, tailored to gaps in their knowledge [33]. This intervention demonstrated significant improvements in CCS’ information needs and self-efficacy to manage their cancer care [34]. Additionally, there is a need for international policies and standards to facilitate better transition to survivorship care for adult survivors of childhood cancer, as well as better communication training for HCPs.

#### 4.1 | Strengths and Limitations

One of the major strengths of this study is its multi-national scope, encompassing participants from 17 countries, representing diverse healthcare settings. This allowed for a more compre-

hensive understanding of survivorship care practices and unmet needs across different cultural and socioeconomic backgrounds. Given 80% of childhood cancer patients reside in countries with limited resources [35], studies including only HIC samples fail to account for the majority of childhood cancer patients [36]. The limited representation of CCS and parents living in LMIC is a major limitation. Despite efforts to disseminate the survey widely, barriers to participation from LMICs—such as language, internet access, and awareness—may have contributed to the low response rate. This limitation precludes a more in-depth, comparative analysis between HIC and LMIC countries. Future research should prioritize targeted strategies to engage participants from LMICs, such as partnerships with local organizations, tailored recruitment efforts with culturally sensitive social media packs, additional language translations, and both digital and paper-based surveys to better address this critical gap in the evidence. Several lessons were learned from the dissemination of this WHO survey and are discussed further elsewhere [29].

Our reliance on convenience sampling and snowballing methods limits the external validity of the findings. As the survey was disseminated internationally via the WHO website, social media, and professional networks without direct recruitment, it was not possible to determine the total number of individuals reached (the denominator) or calculate a response rate. In addition, there may have been selection bias, as participants who are more engaged with cancer support networks or have better access to the internet may be more likely to participate. These methodological limitations should be considered when interpreting the results

The cross-sectional nature of the study also limits our ability to draw causal inferences. The reliance on self-reported data may result in recall bias or social desirability bias, particularly when reporting on sensitive topics such as emotional needs and mental health support. There may also have been potential variability in participants’ understanding of terms such as “late effects” and “long-term follow-up care,” as these were not explicitly defined within the survey. While the questions were phrased to align with typical clinical discussions, differences in literacy, knowledge, and cultural context may have influenced participants’ responses. Future studies should consider including standardized definitions or explanations to ensure consistent understanding across diverse populations. Additionally, though validated surveys were used where possible, they were not available for all domains explored. As such, the findings should be considered exploratory and hypothesis-generating, with future research focusing on refining and validating questionnaires to improve the internal validity of subsequent international studies. Finally, while it was a strength that the study was available in three languages, the study’s focus on English, French, and Spanish speakers excluded non-speakers of these languages, potentially limiting the generalizability of the findings to the broader international population of CCS and their families.

#### 4.2 | Clinical Implications

The study findings have several important implications for clinical practice. First, they underscore the need for HCPs to prioritize discussions regarding emotional well-being and mental health support as integral components of survivorship care. This could

involve the development of targeted training programs to enhance the supportive skills of clinicians and increase their confidence in addressing CCS' psychosocial challenges. Second, our results highlight the importance of providing clear, comprehensive information about late effects and the necessity of follow-up care to CCS and their families. This could be facilitated through the creation of accessible educational materials and resources, as well as incorporating discussions about long-term health risks and management strategies into routine follow-up visits. These topics would be important to revisit as CCS mature, irrespective of whether the parent had previously been informed.

### 4.3 | Future Research

Future research should focus on exploring barriers to accessing survivorship care, particularly in LMICs, and identifying strategies to overcome these challenges at the patient and health-system level. There is a pressing need for international studies that are more inclusive, with effective strategies to improve participation rates from LMICs as well as underserved regions in HICs [37]. Achieving a more representative international sample will help to ensure that findings are generalizable across different healthcare systems and cultural backgrounds, providing a clearer picture of the international state of survivorship care. Additionally, future studies should focus on developing and evaluating interventions tailored to the specific needs of CCS and their families in different regions, considering factors such as access to healthcare resources, cultural attitudes toward survivorship care, and existing support structures. By conducting more comprehensive and inclusive research, the international community can better understand and address the disparities in survivorship care and support CCS and their families worldwide.

### 5 | Conclusions

This multi-national study highlights significant unmet information and psychosocial needs among CCS and their parents, indicating a critical gap in current survivorship care practices. Despite the known prevalence of late effects and the importance of survivorship care, a substantial number of CCS do not access these services and remain uninformed about potential long-term outcomes. These findings highlight the need for HCPs to prioritize discussions about emotional well-being and mental health support as integral components of survivorship care, and to provide clear, comprehensive information about late effects and the necessity of follow-up care. Continuing to engage with CCS and parents with lived experience is critical to inform our understanding of gaps in care on an international scale. By addressing such gaps, we can improve the quality of international survivorship care, and enhance long-term outcomes for CCS and their families.

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### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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