ORIGINAL RESEARCH

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Optimizing childhood oncology care transition from pediatric to adult settings: A survey of primary care physicians' and residents' perspectives

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Abstract

Purpose: The majority of childhood cancer survivors suffer from late adverse effects after the completion of treatment. The prospect of most survivors reaching middle-age is a relatively new phenomenon, and the ways by which current and future primary care physicians (PCPs) will address this novel public health challenge are uncertain.

Methods: A survey assessing knowledge level and information delivery preferences regarding long-term follow-up guidelines for adult patients having survived a childhood cancer was distributed by e-mail through the Quebec (Canada) national associations of PCPs and residents (n=238).

Results: Participants reported an estimated average of 2.9 ± 1.9 cancer survivors in their yearly caseload, and only 35.3% recalled having provided services to at least one survivor in the last year. Most participants indicated ignoring validated follow-up guidelines for these patients (average score 1.66 on a Likert scale from "1—totally disagreeing" to "5—totally agreeing"). Scarce access to personalized follow-up guidelines and lack of clinical exposure to cancer survivors were identified as main obstacles in providing optimal care to these patients (respective averages of 1.66 and 1.84 on a Likert scale from "1—is a major obstacle" to "5—is not an obstacle at all").

Conclusions: The PCPs and residents rarely provide care for childhood cancer adult survivors. On an individual basis, there is a clear need for increased awareness, education and collaboration regarding long-term care of childhood cancer adult survivors during medical training. On a more global basis, structural, organizational and cultural changes are also needed to ensure adequate care transition.

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Introduction

Childhood cancer cure rates represent a standard in oncology research and care [1]: within a few decades, five-year survival rates went from less than 20% to more than 80% [2]. The use of more aggressive treatments explains this success, with the downside being significant long-term side-effects in most survivors. Treatment-related late adverse effects (LAE) can affect numerous organs and functions, often leading to disabling diseases [3,4]. Data from the main survivor cohorts suggest that long-term survivors remain at higher risk of suffering from severe health problems in adulthood compared with their siblings, and that this risk does not seem to reach a plateau [5,6]. These LAE are treatment-related in several ways: in a general manner with specific molecule exposure (e.g., cisplatin and ototoxicity); in a more specific manner with respect to physical exposure (e.g., limb salvage surgery, irradiation of specific body areas); or to cumulative doses administered (e.g., anthracyclines cumulative dose and cardiotoxicity). To optimize care to survivors, several national and international consortiums have developed long-term, specific care guidelines based on treatments received by patients [7,8].

As with other pediatric chronic diseases, while still having its specific challenges [9], the initial follow-up of childhood cancer patients reaching full remission typically takes place in pediatric hospital settings. This implies that at a time of psychosocial change (from adolescence to adulthood), young survivors are also involved in the transition process that will make them adult patients [10]. The role of primary care physicians (PCPs) in facilitating this transition process appears to be pivotal. Evidence from the transition of care literature in the context of adult-onset cancer indicates that most physicians appear to lack basic knowledge of and exposure to cancer survivors during medical training. This applies to PCPs [11,12] and residents [13], but also to oncologists themselves [14], including pediatric oncologists [15,16]. Furthermore, despite the Institute of Medicine statement more than a decade ago calling for more standardized survivorship care [17], the optimal transition and follow-up care model has not been established [18-21], leaving PCPs with uncertainty pertaining to the extent of their role and responsibilities. In addition, there is still no mandatory, standardized way for Canadian oncologists to communicate required follow-up guidelines to either the PCPs or the patients themselves. Thus, the format and extent of transition-related information is left to the oncologists' preferences and goodwill. This is reflected in a high variability in providing survivors and/or PCPs with written survivorship care plan (SCP) when the oncologist-patient relationship is over [12,14,22]. This variability occurs

despite previous studies that have highlighted the positive impact of providing SCP to patients and/or PCPs at transition time on quality of follow-up care [14,22,23], willingness [12,24] and confidence of PCPs in providing high-quality care [18,22,23].

Although transition of care is a challenge for several pediatric chronic diseases [25], other aspects need to be considered when dealing with pediatric cancer survivors [9]. First, young childhood cancer survivors have always been under the close care of their parents, who ensure attendance at follow-up appointments and related duties. This can change abruptly once the patient transitions to an adult care setting. As a result, more perceptive strategies might be required from both PCPs and oncologists during the transition period to ensure adequate follow-up of patients as they gradually gain personal autonomy, and to prevent the erroneous perception that they are "cured for good" [26]. Secondly, as treatments improve, lifespan expectancy rates are also expected to improve. Current follow-up guidelines are based on evidence from the study of patients who were treated decades ago, with different treatment protocols. The latest studies extrapolating long-term side effects in survivors having received treatments equivalent to contemporary therapies [27] suggest that long-term follow-up (LTFU) guidelines will evolve with newer treatments. The PCPs will have to update their knowledge accordingly, which represents a time- and energy-consuming task for a small subset of their caseload. For all these reasons, high-quality, tailored, efficient and dynamic transition information delivery to PCP should be prioritized as an individual-based strategy. Structural, organizational and cultural changes will also be required to implement comprehensive, sustained transition of care processes.

The first objective of this study was to evaluate the knowledge of current and future PCPs (family medicine residents) regarding childhood cancer adult survivorship-related care. The second objective was to determine the barriers and preferences regarding the communication of transition information by oncologists and the models of long-term care.

Methods

Study and questionnaire design

The initial French version of the questionnaire was inspired by a previous study by Henderson and colleagues [16]. An English version was also produced and validated. A bilingual e-mail was sent to pediatric oncologists in each Canadian province; they were asked to send comments and suggestions in order to improve the face validity of the

survey. Comments from six pediatric oncologists were needed to achieve interindividual agreement with the questionnaire, and these comments were integrated to produce a new version of the survey. The second version was then submitted to two PCP, trained and practicing in Quebec, also with the aim of further improving face validity. The final version of the questionnaire was made accessible online, in French and English, via the Research Centre of the Sainte-Justine University Hospital's official website, along with access to the bilingual Ethics Board's approval certificate for this research project.

The final version consisted of the questionnaire covering the main components of the Canadian Institutes of Health Research knowledge transfer framework (2005; <http://www.cihr-irsc.gc.ca/e/29418.html#6>) for the action cycle part: knowledge assessment (opinion questions on burden of health problems, screening of late effects), knowledge assessment within the province's context (the role of PCP in assuming related care), barriers to assessment (obstacles to adequate PCP care of survivors), and selection/tailoring of interventions (preferred information methods regarding survivors' care). Opinion questions were rated on a Likert scale ranging from 1 to 5, with associated labels specified for each set of questions. There were also a set of demographics and questions related to clinical practice. Participants had the option of communicating personal reflections on the topic. Those who did not have any childhood cancer survivors in either their past or current caseload were clearly instructed to answer in accordance to what they would most likely do or think if they were caring for such patients. As a reward for their participation, participants had the option of entering a draw at the end of the survey, where they could win an electronic reading device.

Participants

We collaborated with national (provincial) physician organisations' leaders from the *Fédération des médecins omnipraticiens du Québec (FMOQ)* and the *Fédération des médecins résidents du Québec (FMRQ)*. The invitation to take part in the survey was sent twice to their respective association members, via e-mail lists. For the FMRQ, the invitation was sent only to family medicine residents. The survey was also publicized by the regional health care administration representatives (*Agences de santé et de services sociaux régionales*), who sent invitations to their members via e-mail. Although 29.9% of family doctors in Canada in 2018 were internationally-trained MDs, that proportion was less than 10% in Quebec [28]. The PCPs participating to our survey

were thus assumed to have received their training in Quebec for the majority.

Data analyses

Basic descriptive statistics and unpaired t-tests comparing PCPs and residents' results were performed using SPSS 17.0. Remarks in the comments section on the survey itself (e.g., with French to English translation by the authors: "good research topic", "interesting topic", "would have been interesting to provide a reference link at the end of the survey"), were not analyzed further. For the remaining qualitative material, a thematic analysis of the comments was performed independently by both authors and concepts identified by both of them were retained.

Results

A total of 238 participants completed the survey (Table 1). When asked whether they had performed a medical examination and/or had provided follow-up care for at least one survivor in the last year, only 35.3% answered "yes". Without specifically asking for their total and detailed caseload, participants estimated that they were seeing 2.9 (± 1.9) survivors per year.

A significant proportion of PCPs and residents were unaware of long-term medical complications related to childhood cancer and management-related resources (Figure 1). Most participants provided neutral answers ("don't agree, don't disagree") to questions related to their perception of the burden of long-term side-effects in survivors. Although the two options were not specifically compared in the survey, there was a trend in favor of PCP-lead screening vs. academic hospital-based screening. Results suggested that both PCPs and residents generally felt unaware of screening guidelines and related management relevant to this population.

The PCPs and residents identified knowledge-related barriers as the main obstacles to providing optimal LTFU to adult survivors of childhood cancer (Figure 2). Lack of exposure to these patients and absence of guidelines, both general and personalized, were the obstacles most often perceived as problematic by both PCPs and residents. Logistical issues (access to the referring oncologist or other specialized health professionals) appeared less challenging. Discussions related to psychosocial issues associated with survivorship were the least associated with difficulties in providing adequate care to survivors.

TABLE 1. Participants' profile

	n = 238	%
Gender		
Female	183	76.9
Male	54	22.7
Prefers not to answer	1	0.4
Preferred language		
French	213	89.5
English	25	10.5
Professional status		
Resident in family medicine	147	61.8
PCP	91	38.2
Training year (residents)		
1st year	71	29.8
2nd year	67	45.6
3rd year	9	6.1
Number of practice years (PCPs only)	90	19.6 ± 11.2 ^C
PCPs' principal practice setting		
UMF or GMF ^A	35	38.5
CLSC ^B	18	19.8
Private setting	17	18.7
Non-university affiliated hospital	10	11
University-affiliated hospital	7	7.7
Other	4	4.4

Abbreviations: CLSC, Centre local de services communautaires; GMF, Groupe de médecine familiale; PCPs, primary care physicians; UMF, Unité de médecine familiale

Footnotes:

^A GMF and UMF, associated groups of PCPs

^B CLSC, government-based local service in non-hospital setting

^C Average ± standard deviation

A SCP provided by treating oncologist was identified as the optimal method to efficiently reach out to PCPs and residents (Figure 3). Information provided on a one-to-one professional basis (between a specific PCP and a specific oncologist, regarding a specific patient) was globally graded as the preferred resource. There was no major difference in preferences with respect to receiving general care guidelines in a paper or an electronic version. Privileged access to survivorship specialists was globally graded as the means least likely to be used by both PCPs and residents.

A total of 43 participants (18.1% of respondents) commented in the optional personal reflections box. Eighteen of these comments reflected individual appreciation of the survey, and were not analyzed further. The most common theme in the comments was related to either having received highly useful resources from the pediatric oncologist of their survivor patient(s) (n=4) or what they wished they would receive in such a situation (n=6). Four additional participants wrote similar comments, but it was not possible to determine if they had received such resources or if they wished for such resources. In these 14 participants' comments, three concepts were addressed a total of 13 times: clarity, specificity (i.e., "personalized"), and precision. These comments primarily acknowledged how useful receiving a summary was or their desire for one (n=6), the need for clinical recommendations (n=9) and what to look for in the follow-up (n=6). A few of those 14 participants referred to more than one of these themes.

Discussion

This study surveyed Quebec (Canada) PCPs' and residents' perspectives regarding the care of adult long-term survivors of a childhood cancer. Expressed preferences regarding transmission of information to ensure optimal care to this population, and roles to be assumed by physicians of varying specialties, will drive future long-term survivorship care programs, and thereby ensure optimal survivors' follow-ups.

The level of knowledge of PCPs and residents with respect to LAE in childhood cancer survivors seems insufficient: this finding is in accordance with what has been previously described elsewhere [12,13]. Not surprisingly, most participants expressed their lack of training in caring for and managing survivors' LTFU. Our results indicate that most clinicians surveyed would assume a leading role in LTFU if they were provided with proper transition information by the treating oncologist. Of note, when asked if they would use supplemental resources intended for clinicians regarding the care of these patients, the majority (n=208/87.4%) answered "yes". Other participants indicated

FIGURE 1. PCPs and residents' opinions regarding different aspect of burden of care in adult survivors of childhood cancer.

Questions asked: Medical complications related to the past medical history of childhood cancer in this group of patients are typically: minimal and/or benign (A), rare (B). Because of their medical history, these patients typically require additional medical interventions (C; $p = 0.006$). These patients' long-term medical complications should mainly be screened: by PCPs (D), in academic hospital settings (E). I am aware of and/or know where to find PCP-targeted guidelines for the care of these patients (F). Personally, I feel well prepared to screen medical complications (G) or to provide medical follow-up (H) for these patients. I believe that these patients do not require a follow-up that is more demanding than what I already provide on average to my patients (I).

* : statistically significant unpaired t-tests comparing PCPs and residents for a statement. PCPs, $n=91$. Residents, $n=147$.

Abbreviation: PCPs, primary care physicians

that they would not use these resources because of a lack of time ($n=17/7.1\%$), a lack of interest ($n=3/1.3\%$), or because of a lack of both time and interest ($n=10/4.2\%$). These results suggest that PCPs-lead LTFU is a promising avenue to explore, concomitant with the standardized, dynamic surveillance guidelines provided by oncologists.

Convincing PCPs to provide care for cancer survivors, whether childhood- or adult-onset, does not seem to be an insurmountable challenge, provided PCPs receive appropriate guidance and information *a priori* [18,24]. Unfortunately, studies evaluating optimal strategies of

information transmission between PCPs and oncologists (SCP, shared care, etc.) remain scarce [20,21]. With childhood cancer survivors often not themselves aware of their health-related risks [26,29], or remaining uninvolved despite opportunities offered [30,31], chances of adequate follow-up appear even poorer.

In contrast to results reported in a similar Canadian study assessing PCPs' opinion regarding follow-up of adult-onset cancer survivors [24], expedited access to oncologists did not appear as important as receiving guidelines to participants in our study. This could reflect the fact that a

FIGURE 2. PCPs and residents' thoughts regarding potential obstacles to providing optimal long-term care to adult survivors of childhood cancer.

Statement: To what degree is each of the following elements an obstacle to the adequate medical care of survivors?

- A. Absence of clear, personalized recommendations.
- B. Insufficient experience with the care of these patients.
- C. Absence of clear, generalized guidelines.
- D. Insufficient awareness by PCPs of the specific care needs of these patients.
- E. Insufficient amount of time dedicated to this topic during medical training.
- F. Insufficient amount of time dedicated to this topic during continuing medical education.
- G. Insufficient access to an oncologist.
- H. Insufficient access to mental health services.
- I. Feeling that medical history details as reported by the patient are unreliable.
- J. Insufficient access to related specialist doctors.
- K. Insufficient amount of time to dedicate to these patients ($p = 0.002$).
- L. Patients' reluctance to discuss their medical history.
- M. Discomfort discussing medical history-related fears and anxieties.

* : statistically significant unpaired t-tests comparing PCPs and resident's opinion of a specific obstacle. PCPs, n=91. Residents, n=147.

Abbreviation: PCPs, primary care physicians

FIGURE 3. PCPs and residents' transition information delivery preferences.

Statement: For each of the following possible resources, please indicate if you would agree to use them in your practice if they were available?

- A. Personalized follow-up guidelines provided by pediatric oncologist.
- B. Personalized summary of medical history and complications provided by oncologist.
- C. General care guidelines available from a website.
- D. Printed general care guidelines.
- E. Telephone consultation opportunities with doctors specialized in the care of survivors.
- F. Continuing medical education sessions dedicated to the care of survivors.
- G. E-mail/Internet chatting sessions with doctors specialized in the care of these patients.

There were no statistically significant ($p < 0.05$) result (unpaired t-tests comparing PCPs and residents for each statement). PCPs, $n=91$. Residents, $n=147$.

Abbreviation: PCPs, primary care physicians

majority of our respondents were residents, who might have limited experience with uncertainties and express a different desired level of professional support pertaining to this kind of highly specialized follow-ups. The impact of clinician's experience on willingness to lead LTFU has been demonstrated elsewhere [11]. The SCP was, nevertheless, found to be the preferred modality of information

transmission in an earlier study by Cheung and colleagues, consistent with our own results and those of others [12].

At the end of the survey, participants were invited to provide general thoughts and comments on topics previously covered. Based on the findings reported in Figure 3, the optimal transition information should be personalized and highly oriented rather than referring only to general

guidelines. One participant underlined the fact that having PCP-based rather than oncologist-based LTFU might help survivors to cope with their cancer history more easily. Given the potential impact of survivorship on psychosocial issues and the complexity of environmental factors influencing patients' involvement in their LTFU [9,32], this hypothesis should be tested in a randomized controlled study comparing different follow-up strategies.

The sample size and the non-randomized methodology are the main limitations of this study. The challenge in reaching out to physicians has been raised elsewhere [31]. The sample size and the recruitment method did not allow for the extensive statistical modelling that could highlight factors associated with poor interest and/or knowledge regarding survivorship. For instance, it would have been interesting to explore potential differences between primarily French-speaking and English-speaking physicians and residents, as they are typically trained in different universities and hospitals.

The methodology used in this study could not avoid selection bias and, as a result, it is possible that those who participated in the study were more likely to have interest and/or curiosity for survivorship issues. Despite significant help from national medical associations (FMOQ, FMRQ) in publicizing the study, participation rate remained substantially below expectations. The absence of individual incentives, the lack of knowledge regarding the survey topic and high solicitation rate could all have contributed. Finally, our findings might not apply to private health care systems, as patients in Quebec (and throughout Canada) benefit from universal health care coverage.

An adequate transition of care is essential in ensuring an optimal long-term follow-up for any childhood-onset disease [10], but even more so for cancer survivors, given their specific LAE risks that differ from those of the (cured) primary illness. This is essential from an individual standpoint, and from a public health perspective as well. With growing numbers of aging adult survivors of a childhood cancer requiring more health services, additional costs could rapidly become an issue [6,33].

It needs be emphasized that efficient solutions for transition of care for patients with a pediatric chronic disease cannot be the sole responsibility of the patient or of a single physician. Even though it has been suggested that a patient's characteristics can influence care outputs and outcomes [34], reaching the goal of efficient transition of care requires participation of both the patients and their medical teams. The actions of individuals need to be supported by innovative structural, organizational and cultural changes. This is especially true in Quebec, where approximately 25%

of the patients ≥ 12 years old do not have access to a PCP [35]. Finally, the LTFU guidelines vary slightly across different countries and there are insufficient data about the implementation of those guidelines in different Canadian pediatric oncology centers. Concerted institutional efforts, rather than individual initiatives, will be required to harmonize guidelines and implement a province-wide survivorship care model.

Evidence indicates that PCPs are willing, but not adequately prepared or assisted, to assume leadership roles in these patients' follow-up. The solution to this problem is four-fold. First, it will require integrated training in PCPs' residency curriculum to raise awareness of the needs of this population and to introduce currently available guidelines. Second, SCPs provided to PCPs by oncologists will need to become a mandatory standard of care. Third, guidelines need to be communicated to PCPs in a dynamic fashion, as the screenings that are recommended are likely to evolve with upcoming treatments and related LAE. Last, but certainly not least, ways to encourage patients to become more knowledgeable about their disease and their own best advocates with their PCPs will have to be implemented.

(A)

Acknowledgements

Research involving human participants

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration (and its later amendments) or comparable ethical standards.

Informed consent

Informed consent was obtained from all participants included in the study. Access to our institutional review board acceptance letter was additionally made available online, in French and in English, to all participants.

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