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Research

Transition from pediatric to adult aftercare for survivors of pediatric cancer in Newfoundland and Labrador: a qualitative study

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Abstract

Background: Childhood cancer survivors (CCSs) face increased risks during the period when they leave pediatric care and transition into adult-focused aftercare. We examined the experiences of CCSs entering adult-focused aftercare to gain a better understanding of current transition practices and barriers to transition, and to identify opportunities for improving care.

Methods: We conducted a qualitative study using in-person and telephone semistructured interviews. Childhood cancer survivors who recently transitioned out of pediatric care and health care providers (HCPs) who provide care for CCSs in Newfoundland and Labrador were identified using purposive sampling. Participants were interviewed between July 2017 and March 2019. Data were analyzed using both qualitative descriptive and thematic analysis.

Results: We conducted interviews with 5 CCSs and 9 HCPs. All CCSs interviewed reported receiving aftercare through their pediatric oncology program; only 2 reported receiving any form of aftercare in the adult setting. The lack of a structured transition process for CCSs in the province emerged as a theme in this study. Interview participants identified several barriers to transition: the added challenges for survivors in rural areas, changes in the availability of services after the transition to adult-focused aftercare, challenges associated with navigating the adult system, and a lack of education on transitioning into adult aftercare.

Interpretation: We found that there was little preparation for the transition of CCSs into adult care, and their aftercare was disrupted. Programs serving CCSs have opportunities to improve care by standardizing and better supporting these transitions, for example through the development of context-appropriate educational resources.

Advances in the treatment of childhood cancer have led to substantial increases in the number of patients who survive their cancer and live well into adulthood;[1–5] however, approximately two-thirds of these childhood cancer survivors (CCSs) will be negatively affected by their past cancer or by late effects of its treatment.[6,7] Because of these elevated health risks, it is recommended that CCSs be followed throughout their lives by appropriately trained health care providers (HCPs).[6,8–10] This period of surveillance care is called follow-up care or aftercare.

In Figure 1, we present a model we developed on the basis of our previous work that illustrates the typical treatment progression for a CCS, to highlight the place for transition and aftercare (the follow-up care patients receive after active disease treatment ends) (Devonne Ryan, Paul Moorhead, Roger Chafe, Memorial University of Newfoundland and Eastern Health: unpublished data, 2017).[5] After the onset of cancer and its symptoms, the cancer is diagnosed and treated. After treatment ends and the patient has no active cancer, there remains a lifelong risk of cancer recurrence and negative impacts from receiving cancer treatment.

Aftercare is dedicated to monitoring for recurrences and monitoring for and managing late effects. When CCSs become adults is a key time point for ensuring the continuance of aftercare: at this time, they usually leave the pediatric programs where they received their cancer treatment and initial aftercare and transition into the adult-focused health care system.[11] Despite the clear health benefits to CCSs of continuing to receive aftercare in adulthood, including receiving care to manage late effects of cancer treatment, there are many challenges to maintaining optimal patient care during the transition into adult care.[12–14]

Although it is recognized that this transition is a critical period for CCSs, we found few rigorously conducted, detailed studies of how this transition occurs and barriers to transition during a recent systematic review of aftercare programs.[5,15] Similarly, a limited number of evaluations of interventions have focused on supporting the transition of CCSs, especially

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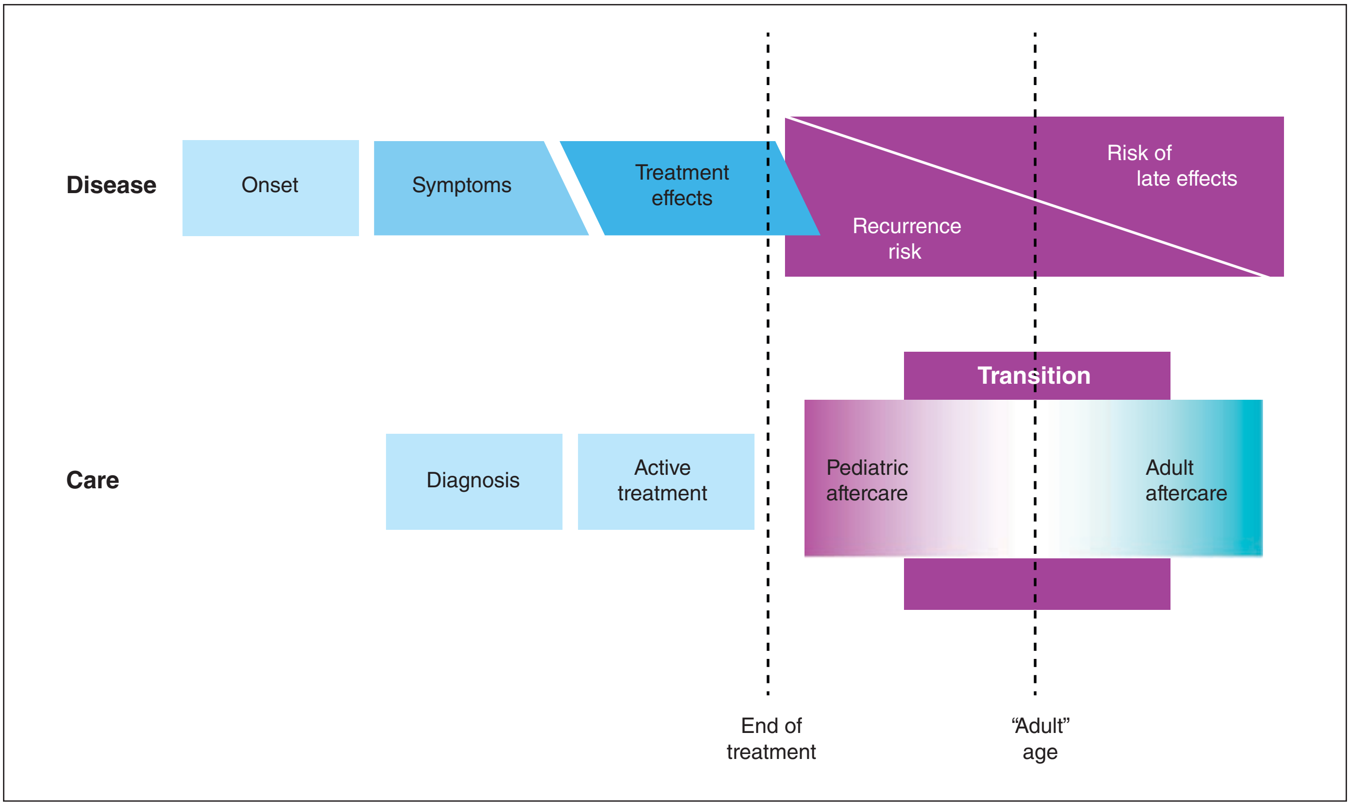

Figure 1: Disease and treatment progression for childhood cancer survivors. "Adult" age indicates the time at which childhood cancer survivors transition to adult aftercare. This can occur when they reach the age of 18 years or when they are 10 years off treatment (whichever is later), or after they reach 18 years of age but before they are 10 years off treatment and they are deemed ready to transition by the pediatric oncologist.

interventions not limited to a single aftercare program.[12,16,17] Our objective in this study was to conduct an in-depth examination of current transition practices for CCSs across Newfoundland and Labrador to better understand current transition practices, identify barriers to transition and find opportunities for improving survivorship care.

Methods

Study design and setting

We used a qualitative research design based on key informant interviews following the Consolidated Criteria for Reporting Qualitative Research (COREQ).[19] In this study, we explored current transition practices in the Canadian province of Newfoundland and Labrador. We focused on Newfoundland and Labrador for several reasons. It has a relatively small population (521 542) in a large geographic area (405 720 km^2) with many rural and remote communities.[18] Newfoundland and Labrador has only 1 pediatric cancer program, located in its capital city, which treats patients from across the province. As in the rest of Canada, Newfoundland and Labrador has a public health insurance plan that provides universal coverage for pediatric and adult follow-up cancer care.

The pediatric oncology program at the Janeway Children's Health and Rehabilitation Centre (often referred to as the Janeway) provides pediatric oncology services for the entire province. It manages between 12 and 18 new pediatric cancer cases per year. Given the small size of the program, its HCPs often develop lasting relationships with their patients, and the program has high rates of retention in its pediatric aftercare program. However, it is unclear how and to whose care survivors transition when they enter the adult-focused health care system across the province. Additional information is needed about current transition processes to identify contextually appropriate interventions to improve the transition and aftercare for these survivors.

Study participants

Study participants were pediatric-focused HCPs, adult-focused HCPs and CCSs who had knowledge and experience with the transition of CCSs into adult care in Newfoundland and Labrador; they were identified and recruited using purposive sampling.[20,21]

Pediatric-focused HCPs were recruited from the pediatric oncology program at the Janeway. The adult-focused HCPs were recruited from either the Dr. H. Bliss Murphy Cancer Centre or the Health Sciences Centre, both located in St. John's. Health care providers in Newfoundland and Labrador who were involved in the care of CCSs, while they were in either pediatric or adult care, were initially identified by the members of the research team, which included a local pediatric oncologist (P.M.). The list of potential HCP participants was then reviewed by a manager in the Janeway pediatric oncology program, who identified additional HCPs. Potential

HCP participants included pediatric- and adult-focused oncologists, a family physician, a physiotherapist, a psychologist, an oncology nurse, a dietitian and social workers. Potential HCP participants were contacted by the research team via email.

A research nurse working with the Janeway pediatric oncology program identified CCSs who were eligible for the study. Childhood cancer survivors were eligible if they had cancer diagnosed before they were 18 years of age, they had completed their care at the Janeway, they were considered survivors of childhood cancer by their pediatric oncologist and they were currently over the age of 18 years. These CCSs were contacted directly by the Janeway pediatric oncology program, by letter and telephone, and informed about the study. Childhood cancer survivors who were interested in participating were asked to contact one of the authors (D.R.) directly to arrange for an interview. Having the Janeway program make the initial contact with the CCSs limited the amount of personal health information that needed to be shared with the research team to facilitate recruitment.

Data sources

Separate semistructured interview guides were developed for both CCSs and HCPs (Appendix 1, available at www.cmajopen.ca/content/9/2/E309/suppl/DC1). D.R. and R.C. developed the questions to meet the study objectives and to examine the gaps we and others identified in previous literature reviews.[5,15] The interview guides were approved by the entire research team before being used.

Participants were given background information about the research project and the objective of the study before the interviews. One female investigator (D.R.), a doctoral student with experience in conducting qualitative interviews, conducted all of the interviews. Interviews were conducted in person or by telephone, depending on participants' availability and location. The interviewer took field notes throughout the interview. The interviews were audio recorded using the QuickTime Player application and were transcribed verbatim by a professional transcriptionist. Interviews were conducted in Newfoundland and Labrador between July 2017 and March 2019.

Data analysis

We used qualitative descriptive and thematic analysis to analyze the interviews. Qualitative descriptive analysis was used in this research to identify factual information about current transition and aftercare processes.[22] For the identification of barriers to improved transition, we used thematic analysis, which provided a structured method for identifying, organizing and describing the themes related to barriers and opportunities.[23,24] To get familiar with the data from each interview, we reviewed the entire interview transcript before starting the coding process. We then manually coded each interview transcript. Data were initially coded by 1 member of the research team (D.R.). The coding was then reviewed and confirmed through discussions with the other authors (R.C., P.M.).

After coding was complete, we organized all of the data by code to identify the main themes of barriers.[20] We organized the codes under theme headings (e.g., for the theme "Lack of education surrounding transitions," codes included understanding diagnosis, understanding treatment, understanding need for aftercare, and education needs to start earlier). Once all of the themes were identified, the research team reviewed the transcripts again to ensure that the themes accurately represented the data.

Ethics approval

Ethics approval for the project was granted by the Newfoundland and Labrador Health Research Ethics Authority.[25]

Results

Fourteen interviews were conducted. Interviews were conducted with 5 of the 20 CCSs and 9 of the 12 HCPs who were invited to participate in the study (Table 1). The HCP group comprised 5 adult or pediatric oncologists, 3 allied health professionals (dietitian, physiotherapist and social worker) and 1 family physician. Of the 3 HCPs who did not participate, 2 did not respond to multiple invitation requests and 1 was unavailable for an interview. Interviews were between 15 and 60 minutes in length. To maintain participant confidentiality, the demographic characteristics of the participants were not analyzed further.

All of the CCSs who were interviewed had received pediatric aftercare until they were 18 years of age or older. Only 2 reported receiving aftercare after leaving pediatric care, 1 of

Table 1: Participant characteristics

Characteristic	No. (%) of participants CCS *n* = 5	 HCP *n* = 9
Urban	3 (60)	9 (100)
Female	3 (60)	7 (78)
Previous treatment		
Chemotherapy	5 (100)	NA
Radiation	2 (40)	NA
Aftercare		
Had received pediatric aftercare	5 (100)	NA
Had received adult aftercare	2 (40)	NA
Type of HCP		
Oncologist	NA	5 (56)
Primary care physician	NA	1 (11)
Allied health professional	NA	3 (33)
Work location		
Pediatric hospital	NA	6 (67)
Adult hospital	NA	3 (33)

Note: CCS = childhood cancer survivor, HCP = health care provider, NA = not applicable.

whom reported only being regularly screened for cardiac effects. One CCS was unsure of their specific cancer diagnosis and another struggled to recall all aspects of their treatment; these are key pieces of information that survivors should know to help direct their future aftercare. The HCPs in our interviews did not seem to be aware that a potentially large percentage of young adult CCSs in the province were not receiving aftercare.

The process of transition for CCS

Through our interviews, we identified 3 different points at which transitions to adult care usually occur at the Janeway. Survivors are followed in the pediatric health care system until they reach the age of 18 years or they are 10 years off treatment (whichever is later), or until after they reach 18 years of age but before they are 10 years off treatment and they are deemed ready to transition by the pediatric oncologist. In all cases, decisions about the transition of survivors are made in discussion with the survivor, their family and other HCPs. The transition and aftercare trajectory depend on the CCS' type of cancer, the treatments they received and their geographic location. HCPs stressed that CCSs would receive specific aftercare for particular cancer diagnoses and treatments. For example, CCS 2 received specific aftercare related to potential cardiac late effects of treatment; however, no other CCS we interviewed reported special aftercare arrangements.

The HCPs we interviewed indicated that currently, in Newfoundland and Labrador there is no structured transition program or regular advanced education about transition into adult aftercare. During survivors' last clinic visit at the pediatric centre, the pediatric oncologist would usually verbally review a summary of their care with them, including their original diagnosis, treatments received, risks of late effects associated with treatment and follow-up care needed (e.g., special screening). Similarly, there are no formal transition procedures that allied health providers follow. Depending on their needs, survivors may or may not be followed by allied health providers into adult aftercare.

There are several possible destinations for CCSs after they transition from the Janeway (Figure 2). According to the HCPs we interviewed, a local family physician recently

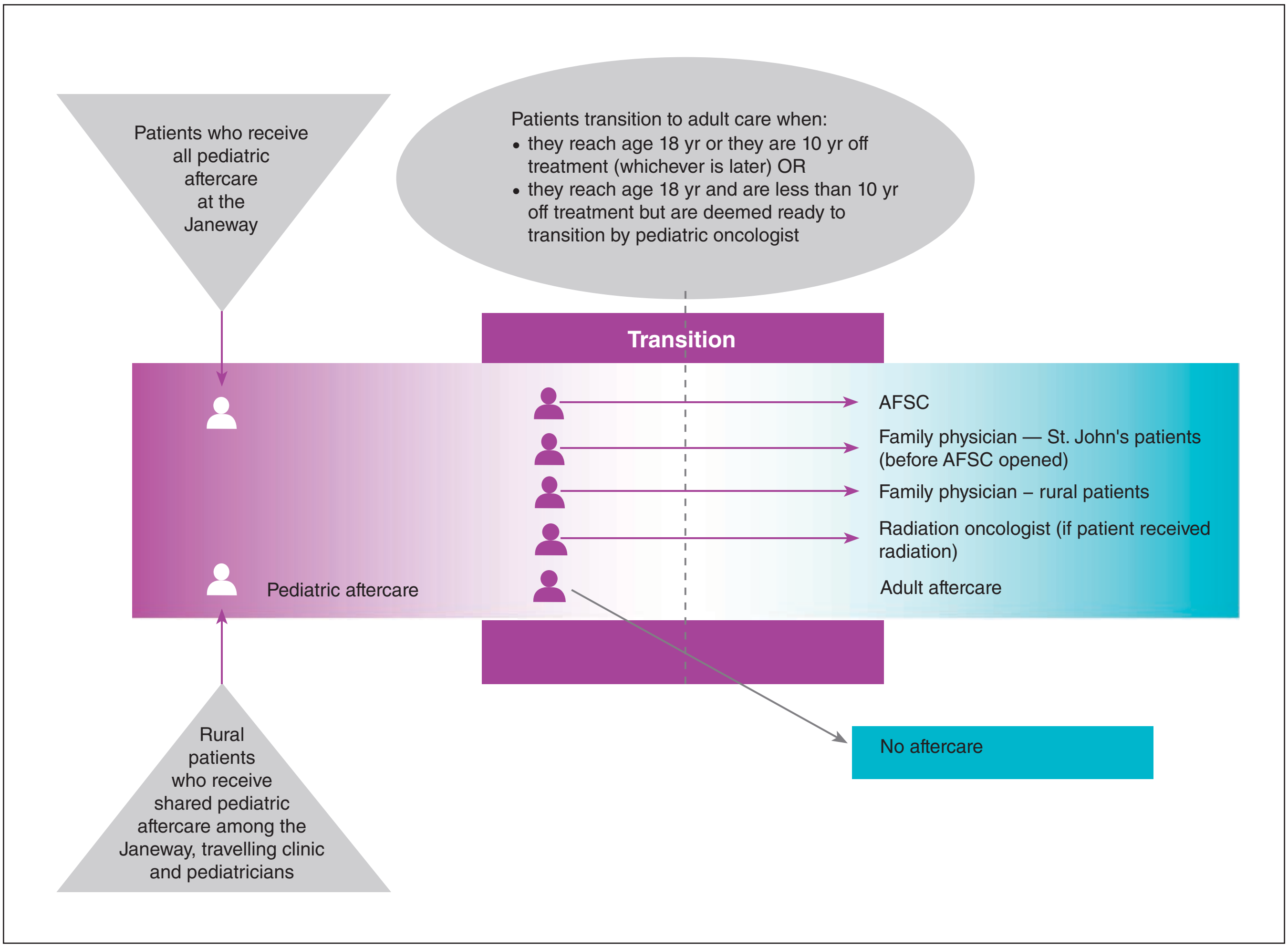

Figure 2: Current transition process from pediatric to adult care for childhood cancer survivors in Newfoundland and Labrador. The travelling clinics were run by the Janeway. Note: AFSC = adult follow-up survivorship clinic, Janeway = Janeway Children's Health and Rehabilitation Centre.

started an adult follow-up survivorship clinic (AFSC). This AFSC has been underway for approximately 3 years, with an estimated 4 or 5 CCSs transitioning to the clinic annually. CCS 4 reported receiving aftercare through the AFSC. If a patient has received radiation as part of their treatment, the radiation oncologist also follows the patient alongside the AFSC. Pediatric oncologists reported that survivors who transitioned before the inception of the AFSC were often referred back to their family physician. Because the AFSC program is in the provincial capital city, CCSs from rural communities are still usually transferred back to their family physician for aftercare. It emerged from the interviews that it is possible that survivors' aftercare arrangements may change over time depending on their location and other circumstances.

Barriers to improving the transition and aftercare

We identified the following barriers to improving CCSs' aftercare experience: challenges for rural survivors, changes in availability of services after transition, challenges with navigating the adult system and lack of education surrounding transitions. Table 2 provides quotes from HCPs and CCSs relating to each theme.

Challenges for rural survivors

HCPs and rural CCSs reported that there are considerable differences in how survivors in rural areas receive aftercare. With no pediatric care hospital outside the capital city, families reported travelling considerable distances to receive care or they received care through travelling clinics operated by the Janeway. Survivors without a family physician in their rural community often rely on pediatric travelling clinics for all their primary care, increasing the challenges associated with transition. After they transitioned out of pediatric care, some participants felt there were a limited number of family physicians available to take over their care. Others reported that family physicians may not have the same understanding of cancer care as the HCPs at the dedicated AFSC. Survivors in rural areas also face inequities of access to allied health services and mental health support. One interviewee said "a new way of doing business" needs to be considered for how aftercare is provided in rural areas.

Changes in availability of services after transition

Pediatric oncologists discussed the importance of the allied health support received by CCSs. They said this support is less accessible to CCSs after their care transitions to their

Table 2: Key themes and illustrative quotes from health care providers and childhood cancer survivors

	Illustrative quotes; type of participant	
Key theme	Health care providers	Childhood cancer survivors
Challenges for rural survivors	I find that on the west coast [of Newfoundland and Labrador], or outside of St. John's, with the patients that we see in our travelling clinics ... the family physicians are so in flux in rural communities that most of these patients don't have a family physician and often we're [the pediatric medical team] the only people that they see. (HCP 2)	It's a big difference [being in a rural community] because it's a 12-hour drive [to the Janeway], so to come in here every year to get the check-up, it was a big deal. (CCS 4)
Changes in availability of services after transition	I wouldn't say "loss of services" … I think that maybe there are some services that are not as emphasized on the adult side. … On the pediatric side, there's a little bit more emphasis on the sort of social work part, school, integration, those sorts of things. That all of those resources are available on the adult side, I just don't think that there's as much emphasis. (HCP 6)	Okay, here's a doctor, here's a psychologist or here's whoever, you could go talk to, but since I haven't had that appointment [since the Janeway], I feel like I'm missing out on a lot of resources ... that could be beneficial to me and even when I was in the pediatric care. (CCS 2)
Challenges with navigating the adult system	I think the biggest problem [is] for patients that are not connected to any place or person. They're not connected to a family doctor because they are moving around the province for school, or the country for school or jobs and so; they're not, they're not grounded anywhere to maintain those connections. I think if you polled most young adults, they would have no idea [how to navigate the health care system]. (HCP 2)	[Be]cause I feel like it was more of a miscommunication in care where maybe one person thought it was being taken care of ... or they thought it was somebody else's job, but I wasn't ever followed up. I was told I would have been and have something in place to transition children from the Janeway to the Health Sciences [Centre], or whatever the hospital that they're seen at. (CCS 3)
Lack of education surrounding transitions	[Childhood cancer survivors] need to have an understanding of what their treatment was, what their diagnosis [was], and what are the important things to remember for their ongoing health. I think if you polled most young adults, they would have no idea. And ask them what they would do, they would all feel the same way. (HCP 1)	I still had a family doctor at that point but there wasn't really any contact between them. ... the whole leukemia thing was kinda dealt with in the Janeway and then like, anything outside of that was just kind of taken care of by my family doctor and he didn't really know anything about the cancer, and they didn't know anything about what was going on with my family. (CCS 2)

Note: CCS = childhood cancer survivor, HCP = health care provider, Janeway = Janeway Children's Health and Rehabilitation Centre.

family physician or to the AFSC. Although ideally the adult health care system should provide all the same services as the pediatric system, the onus is on the patient to arrange for care and manage appointments.

Childhood cancer survivors reported having trouble accessing allied health professionals in the adult system, noting that they experienced long wait times to access services, if they were available at all. Additionally, allied health services for adults are not always accessible under publicly funded health coverage programs. For patients who do not have private insurance, these services can be costly, and not all CCSs are able to pay for them out of pocket. Several CCSs noted that they lost access to psychological supports after leaving the pediatric care setting. One HCP discussed the need for a multidisciplinary cancer aftercare program for adult CCSs to mitigate the loss of these services.

Challenges with navigating the adult system

After transitioning to adult care, CCSs are expected to have a certain level of autonomy, and it is up to the patient to identify their needs and arrange for appointments. Our interview data suggest that CCSs who do not have stable, continuous housing; who do not have a regular family physician; or who rely on their parents to organize their care into adulthood often have challenges navigating the adult health care system. In the adult system, some tools (i.e., patient navigators) are provided to help patients with active cancer to navigate the system, but the CCSs with whom we spoke were unaware of these resources. CCSs felt that they left pediatric aftercare not knowing when they would be contacted by their new provider to receive aftercare within the adult system. CCSs' previous pediatric providers are commonly their first point of contact when issues arise in early adulthood, even though they have transferred out of pediatric care, because CCSs do not know who else to contact.

Lack of education surrounding transitions

Participants said that there is currently no formal preparation for CCSs transitioning to adult care in Newfoundland and Labrador. A pediatric oncologist does provide a medical summary to the physician accepting the CCS and provides the CCS with additional information, including screening appointments (dependent on cancer diagnosis and treatment) and any other pertinent information related to their diagnosis or treatment. This is usually done by the pediatric oncologist who conducts the patient's last clinic visit.

Health care providers and CCSs discussed the need for a site visit with the HCP who will provide the CCS' adult aftercare, before the CCS leaves pediatric care. This would include an introduction to the new HCP and additional information for the patient on how to manage their future health care needs.

Survivors reported experiencing a general lack of communication between the pediatric and adult health care systems. It was suggested that education about aftercare should begin earlier in the pediatric care setting. A more formalized approach would begin before a patient's last pediatric visit and include educating the CCS about their past cancer, developing plans to help them navigate the adult health care system and meeting with the receiving adult HCP. This approach would provide the opportunity to "create a bridge to a new context," according to one of the pediatric oncologists we interviewed. Health care providers recognize the need to prioritize transition; however, there is a tendency for it to get lost among other health care priorities.

Interpretation

We examined the process of transition from pediatric to adult care for CCSs and identified the barriers they face in making this transition in 1 Canadian province, for both its urban and rural populations. We found that the process for transitioning had insufficient structure and lacked dedicated supports. The transition occurred as a discrete event rather than being "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems"[26] which that transition should aim to be.[26–28] Only 2 CCSs reported any form of adult aftercare. This indicates that there is a gap in the care that is essential to the well-being of these survivors. Other barriers to transition identified by the interview participants included challenges for rural survivors, changes in the availability of services after transition, challenges associated with navigating the adult system and lack of education surrounding transitions.

Our findings reflect a situation commonly faced by CCSs. A cross-Canada survey found that 88% of pediatric oncology programs reported following long-term follow-up guidelines but only 35% had access to a formal transition program.[29] Moreover, we found that CCSs in rural communities face additional challenges accessing aftercare. Such inequities in rural health care are prevalent in many jurisdictions.[30] Access to health care facilities influences patient outcomes.[31,32] Direct and indirect costs associated with travel amplify the challenges for rural CCSs.[33] Other studies have compared CCSs in rural communities with gender-matched peers and reported poorer social competence, greater behavioural issues and weaker overall school performance among rural CCSs.[34,35] Strategies that help reduce costs and time of travel, such as telehealth, travelling clinics and other creative services, should be further investigated to better serve CCSs living in rural areas.

Education for HCPs and CCSs is another key feature of successful aftercare. Components of education during the transition of CCSs that have been identified as necessary include knowledge about one's disease, disease treatment, future health risk, self-management skills and coordination of care.[17,28] Our research highlights that CCSs may not have sufficient knowledge to maximize their engagement with the health care system during transition. The Childhood Cancer Survivorship Study found that only 72% of CCSs could correctly recall their diagnosis and only 35% were able to report awareness of any health risks.[2] Ginsberg and colleagues reported similar findings whereby CCSs were unable to report basic information regarding their health.[36]

Some CCSs lack the skills required to advocate for themselves as they progress into adult care.[37,38] Participants in our study were supportive of an educational intervention to improve the transition from pediatric to adult care for CCSs. One direction we will take in our future work is to develop and evaluate an educational intervention relevant to our study population.

Even in a province with a relatively small number of CCSs, we found that providers were not fully aware of their experiences and the challenges they face after they leave pediatric care. Of the 5 CCSs we interviewed, only 2 reported having received any aftercare once they entered the adult system, 1 of whom was followed only by the cardiac program. This is clearly not optimal nor in keeping with standards of aftercare. The providers we interviewed seemed unaware that a potentially large percentage of young adult CCSs in the province were not receiving aftercare.

Limitations

Although our study provides a base from which to make recommendations for improving care, there are some limitations. This qualitative research studied only the transition experience of survivors in 1 Canadian province. Caution should be used when extrapolating these findings to other jurisdictions. It would probably be beneficial if similar work were carried out in other jurisdictions to help identify gaps being experienced by CCSs in other locations.

Although we are confident in the validity of our findings, additional techniques for improving the validity of qualitative research, such as the use of coding software and participant checking, could also have been employed. Despite our best efforts and our use of numerous methods of recruitment, we were able to interview only 5 CCSs. We do not know how those who participated in the study differ in their experience from CCSs who did not participate. Several potential HCP participants approached to participate in the study did not agree to an interview, so we were unable to include their perspectives on the transition to aftercare. Finally, we did not pilot or test our interview guide.

Conclusion

We identified the process by which CCSs transition into the adult health care system in Newfoundland and Labrador and identified the barriers associated with transition. Key stakeholders recognized the need to address the gaps associated with the transition and offered recommendations on how these CCSs can be better supported. Our results show that a clear, more structured process for transition for CCSs is probably needed. Our research also highlights the compounded challenges for CCSs in rural communities. CCSs and HCPs in our study shared a common goal of holistically improving the transition of CCSs from pediatric to adult care. We hope that by improving the understanding of transition practices, the results of this study will support the development of interventions to more adequately prepare CCSs for their transition into early adulthood and their move into the adult-focused health care system.

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