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ORIGINAL ARTICLE

Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care

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Abstract

Purpose Survivors of pediatric cancer are prone to late effects which require ongoing medical care. Young adult survivors often transition from specialist pediatric care to adult-oriented or community-based healthcare. This study aims to describe the attitudes and experiences of survivors and their parents towards transition barriers and enablers.

Methods Long-term survivors and parents (of survivors < 16 years) were recruited from 11 hospitals in Australia and New Zealand to participate in a semi-structured telephone interview regarding their transition experiences. Transcribed interviews were coded and content analysis was used to number participants within themes.

Results Thirty-three participants were interviewed, of which 18 were survivors (mean age 26 years, $SD = 6.3$; mean time since treatment completion 13.3 years, $SD = 6.1$) and 15 were parents (mean survivor age 15 years, $SD = 1.9$; mean time since treatment completion 8.4 years, $SD = 2.8$). Participants described their transition attitudes as positive (55%), neutral (15%), or negative (30%). Key barriers to transition included dependence on pediatric healthcare providers, less confidence in primary care physicians (PCPs), inadequate communication, and cognitive difficulty. Enablers included confidence in and proximity to physicians, good communication, information, independence, and age.

Conclusions Many survivors face barriers to their transition out of pediatric care. Early introduction to transition, greater collaboration between healthcare professionals, and better information provision to survivors may improve the transition process. Future research of survivors' experience of barriers/enablers to transition is needed. Development of interventions, such as those that address self-management skills, is required to facilitate transition and encourage long-term engagement.

Keywords Pediatrics · Oncology · Survivorship · Long-term follow-up · Transition · Cognition

Abbreviations

LTFU	Long-term follow-up
PCP	Primary care physician
HCP	Healthcare professionals
ANZ	Australia and New Zealand
CNS	Central nervous system
ALL	Acute lymphoblastic leukemia

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Introduction

With survival rates for many common childhood cancer diagnoses exceeding 80%, it is estimated that one in every 750 individuals in the USA is a childhood cancer survivor [1]. However, survivors are at risk of developing late-effects, adverse long-term health outcomes after treatment [2]. One study placed the cumulative prevalence of late effects by the age of 35 years at 93.5% for survivors [3], including adverse organ health (e.g., cardiomyopathy), psychosocial sequelae (e.g., mental health and cognitive difficulties), and increased risk of recurrent primary or secondary malignancy [1, 2, 4].

Late effects increase survivors' risk of early mortality and morbidity compared to the general population [5]. Consequently, this vulnerable population requires ongoing anticipatory surveillance and active management through long-term follow-up (LTFU) [6, 7]. Models of LTFU recommend stratifying survivor care by risk of developing late effects, based on a survivor's diagnosis, treatment(s) received and other risk factors [8]. Low-risk survivors may be managed by primary care physicians (PCPs) [9, 10]. Moderate-risk survivors are recommended to receive shared follow-up care (i.e., between PCPs and oncology teams), whilst high-risk survivors are primarily managed by their oncology team, with regular PCP interaction [9, 10].

Moving from pediatric to adult services is commonly referred to as "transition." During transition, care shifts from family-centered pediatric to independent patient-centered healthcare as survivors enter adulthood [6]. Transition to adult or community-based care ideally entails an early and sustained collaborative effort between survivors, their physicians, and the healthcare system [7, 11]. The goals of best practice transition are to (1) provide survivors with versatile and developmentally appropriate education regarding their cancer(s), late effects, and required surveillance [6]; (2) increase survivors' understanding of potential lifestyle changes [6]; and (3) initiate an ongoing relationship between survivors and their follow-up care to encourage lifelong engagement [6]. Ultimately, this helps survivors independently manage their ongoing healthcare needs [12, 13].

There are, however, many barriers to transition which can cause some survivors to become disengaged from follow-up [14]. Up to 75% of survivors have reported not receiving the recommended survivorship-focused care [15–19]. Healthcare system barriers include insufficient medical insurance, inadequate PCP training regarding transition, inaccessibility of care due to distance [7, 12], and in Australia and New Zealand (ANZ) particularly, varying transition practices and pathways [20]. Physician-level barriers include pediatric oncologist reluctance to transition long-term patients into adult care because of their long-standing relationship with them [7], or PCPs poor awareness of LTFU guidelines and risk-based screening [7, 21]. Healthcare professionals (HCPs) also highlight lack of collaboration between HCPs, and unstable social context as potential barriers to transition [21–23]. A survivor's over-reliance on their oncologist and family, or fear of previous relationships with PCPs, can be a barrier at the survivor level [7, 24], as well as limited knowledge of future health risks and poor self-management skills [13, 25, 26]. Cognitive late effects from cancer or its treatment may also impede transition [7, 12]. Impaired cognition increases a survivor's dependency on their family and physician, hindering successful transition [4, 7, 27], as does younger age [13].

Survivors and parents identify enablers to transition including insurance availability, counselling, providers knowledgeable in survivor care, flexible scheduling with a single identified coordinator, and comprehensive care and access to subspecialists [28–30]. Stakeholders recommend transition readiness be assessed in the context of a survivor's illness experience, rather than by indicators such as age [31]. However, there has been limited exploration of transition experiences from survivor and parent perspectives, across countries and health contexts [31]. Therefore, this study aims to describe the barriers and attitudes towards transition from the perspective of survivors and their families when transitioning out of pediatric services and into adult healthcare across ANZ.

Methods

Participants

We selected eligible survivors and their families using electronic medical records of all 11 pediatric ANZ hospitals as part of the ongoing Australia and New Zealand Children's Hematology/Oncology Group (ANZCHOG) Survivorship Study [19]. We mailed questionnaires to potential eligible participants, including an option to participate in a semi-structured telephone interview conducted by a trained researcher. We invited survivors over 16 years of age to participate. For survivors under 16 years of age, we invited their parents/guardian to complete a parent-modified version of the questionnaire/interview. Eligible survivors included those who (1) were diagnosed with some form of cancer before the age of 16 years and at least 5 years prior to participation in this study, (2) had completed active cancer treatment at a participating hospital, (3) were fluent in English, and (4) were alive and in remission. No further limits were placed to capture a broad range of perspectives/experiences. Ethics approval was obtained from all participating hospitals, and informed consent was obtained from all participants before proceeding with the study.

Data collection

Participants self-reported demographic and clinical details in the questionnaire, which included diagnosis, treatment received, time since treatment, and whether they had experienced memory or learning difficulties since completing their treatment. The interview included questions about whether they had visited their PCP for cancer-specific care since completing treatment, who they perceived to be the person primarily responsible for their care, and questions regarding their transition or future transition (Table 1). We conducted interviews March–October 2016.

Data analysis

We conducted descriptive statistics using SPSS software version 23.0 to analyze the demographic information obtained from the questionnaire. For the interview data, we chose qualitative analysis to promote an understanding of the meaning of survivors' experiences [32]. Interviews were transcribed verbatim. Three researchers (BN, JF, CS) reviewed participant responses from interviews for commonly arising themes and categories, resulting in a descriptive coding scheme informed by research aims [32, 33]. Interviews were initially coded line by line using NVivo 11 by one researcher (BN). Two researchers (JF, CS) then independently coded 10% of the final sample ($n = 33$) to ensure the reliability of initial coding (95% agreement). Disagreements were resolved through discussion. Categories of responses were then analyzed and interpreted, resulting in over-arching themes. Transition status was determined by self-reported responses. Survivors' transition attitudes were classified as either positive, neutral, or negative according to the overall perspective of the survivor expressed during the interview. Final coding was double checked by another researcher (JF) on 20% of the final sample, with 86% (1 disagreement out of 7) agreement on categorization of transition attitudes. We used content analysis to identify the number of participant responses to a particular theme [32]. As interviews were semi-structured, not all participants responded to every theme. The proportion of participants who responded to each question is reported as $n/33$ and variations noted in cases where all participants did not respond.

Table 1 Questions from the semi-structured interview schedule

Provision of care

1. Have you seen your PCP for cancer specific care?
2. Who do you believe is the primary person currently responsible for your cancer follow-up care?
3. How confident are you that [person identified in (2)] understands your current and future health needs?

Transition experience

Introductory remarks: explanation/definition of transition

In some LTFU clinics across Australia they do not provide care for adult survivors of childhood cancer for the rest of their lives. They may eventually 'transition' their patients out of that service into the care of an adult specialist or adult oncologist/clinic, or they may discharge them to their GP.

4. Have you transitioned?
   If yes, prompt for: description of transition experience including pathways and reason for transition, perceived appropriateness of transition, confidence in transition and communication between prior and new provider, important aspects and benefits/negatives of transition
   If no, prompt hypothetically: willingness to transition in future, feelings, and perceived benefits/negatives of transition

Results

Of survey respondents ($n = 485$; response rate 59%) [19], 83 survivors/parents opted in for interviews. We purposely sampled 33 participants to discuss their transition, the results of which are presented here. Adult survivors ($n = 18$) were on average 26 years old (SD = 6.3), and parents ($n = 15$) reported on their children who were on average 15 years old (SD = 1.9; Table 2). Survivors were commonly diagnosed with ALL (13/33, 39%) and were interviewed 13.3 years after treatment completion (SD = 6.1). Survivors whose parents were interviewed had completed treatment on average 8.4 years ago (SD = 2.8). Many participants described their overall transition attitude as positive (18/33, 55%), with under one third of participants reporting overall negative transition attitudes (10/33, 30%). Participants who reported that they had transitioned (15/33, 45%) described it as an overall positive experience as they had greater independence, were with other patients their age, and were able to access medical care closer to home. Identified barriers (dependence on oncology, cognitive difficulties, inadequate communication, and low PCP rapport) and enablers (independence, information, older age, communication, and PCP confidence) appeared to shape participant's transition attitudes.

Enablers to transition

Independence

Participants expressed positive transition attitudes when discussing how independence, in the form of self-management skills, could combat attachment to previous HCPs (7/33, 21%). Some participants interpreted self-management skills as being beneficial to the transition process, such that only when the survivor was "ready to go on [their] own…[would they] get transferred to all adult doctors" (female survivor, 20 years). Other participants perceived transitioning as a way of limiting a survivor's "reliance on doctors" (mother of female survivor, 18 years), which would help develop a survivor's self-management skills so it was "not [the parents] taking any responsibility for [the survivor's] care."

Table 2 Demographic and clinical characteristics of participant sample (total $n = 33$)

Characteristics	Parents (total $n = 15$)	Survivors (total $n = 18$)
Survivor's mean age at time of interview, years (SD)	15 (1.9)	26 (6.3)
Location, *n* (%)		
Major city	10 (66.7)	14 (77.8)
Inner regional	4 (26.7)	1 (5.6)
Outer regional	1 (6.7)	3 (16.7)
Transition status, *n* (%)		
Have transitioned	4 (26.7)	11 (61.1)
Have not transitioned	11 (73.3)	7 (38.9)
Self-reported cognitive difficulties, *n* (%)		
Present	5 (33.3)	3 (16.7)
Not present	10 (66.7)	15 (83.3)
Gender, *n* (%)		
Female	5 (33.3)	13 (72.2)
Male	10 (66.7)	5 (27.8)
Diagnosis, *n* (%)		
Lymphoma and leukemia	10 (66.7)	11 (61.1)
Brain cancer	2 (13.3)	2 (11.1)
Other	3 (20)	5 (27.8)
Mean age at diagnosis, years (SD)	2.5 (1.6)	6.8 (5.1)
Mean time since treatment at time of interview, years (SD)	10.5 (1.9)	17 (7.65)
Treatment type, *n* (%)		
Surgical removal of cancer	5 (33.3)	4 (22.2)
Chemotherapy	15 (100)	18 (100)
Radiotherapy	5 (33.3)	10 (55.6)
Bone marrow/stem cell transplant	3 (20)	3 (16.7)
Mean time since treatment completion at time of interview, years (SD)	8.4 (2.8)*	13.3 (6.1)**

*One participant did not complete this part of the questionnaire

**Three participants did not complete this part of the questionnaire

Information

Participants identified that adequate and appropriately delivered information was an enabler of transition (6/33, 18%). Information that enabled transition was seen to provide context "about some of the long-term effects" (female survivor, 22 years) and "the role that [the survivor] needed to play with the PCP." Participants suggested that this information should be delivered early "if [survivors] had questions at say 16-17 as a teen" (female survivor, 27 years), and through an appropriate medium "like a website or…a booklet."

Age

Participants identified older age as enabling transition, relating to positive transition attitudes (9/33, 27%). With older age, participants predicted they "might decide [they don't] want to do [pediatric care] anymore" (parent of female survivor, 18 years), expressing that "adults are a bit different to kids… adult doctors would have a bit of a broader understanding" (female survivor, 36 years). Participants also reported that the younger age of other survivors in clinic enabled transition, as it encouraged them to transition to adult-oriented care. Older survivors who "saw kids that might have been two or three" (female survivor, 19 years) years old felt that they were "not going through the same sorts of things", which encouraged them to transition and be "with people [their] age group."

Good communication

Good communication was perceived to enable successful transition (8/33, 24%) and was associated with positive transition attitudes. Participants expressed that if there was effective communication between past and future HCPs, they would not "have to educate or retell [their medical history] every time [they] went in" (female survivor, 36 years). Communication also provided comfort during transition. Whilst some identified communication with parents as a source of information and security, others suggested that a link to their past HCP could give them comfort during the transition process, such as "a phone call…just to say 'how's it going? Do you have any questions?'" (mother of male survivor, 15 years).

Confidence in and proximity to physicians

Confidence in physicians was an enabler of transition and related to positive transition attitudes (4/33, 12%). Confidence was fostered by familiarity with new specialists.

"They started talking to me about [transition] since I've been eighteen and I was still seeing [my oncologist] when I was twenty…I've known my new hematologist oncologist already…it's not scary like someone new" (female survivor, 23 years). Participants expressed confidence in their PCP when they perceived them as specialized in cancer treatment and understanding of the burden of late effects. These PCPs were described by participants as the central coordinator in their care, setting them "up with the skin specialist and…the physio[therapist]" (mother of male survivor, 12 years). Compared with previous pediatric clinics, participants expressed living in close proximity to PCPs as an enabler of transition (3/33, 9%) as "it meant not having to drive" (male survivor, 20 years).

Barriers to transition

Dependence on pediatric healthcare providers

Dependency on pediatric HCPs was the most commonly reported barrier amongst participants (11/33, 33%). Participants described an attachment to their previous healthcare provider, which appeared to be related to negative transition attitudes. Participants cited two main reasons for this. The first was that "having cancer as a kid [made] you a part of a club" (female survivor, 27 years) where they were treated "like a superstar" (6/11, 55%). Being "transitioned out of that" familiar and nurturing environment gave survivors a sense of loss, as it would "be like…ending something" (female survivor, 27 years). The second reason was the level of understanding past HCPs had about participants (7/11, 64%). This was expressed as "really beneficial, because [the survivor] might not notice a change but [their original HCPs] might" (female survivor, 26 years).

Cognitive difficulty

Twenty-four percent of participants reported experiencing cognitive difficulties (i.e., problems with learning and memory) after cancer treatment (8/33, 24%). Half of participants with cognitive difficulty viewed it as a barrier, reporting negative transition attitudes (4/8, 50%). Cognitive difficulty was expressed as an "intellectual disability" (male survivor, 20 years) that acted as a barrier to transition, keeping the survivor "quite young in a lot of ways." Participants expressed reservations and suggested making transition "a slow process" (mother of female survivor, 16 years) that would help the survivor "understand what [they] had" because their cognitive impairment made communication difficult. This participant also expressed a lack of confidence in PCPs, stressing the need for them to understand "that late effects are a real thing." Another participant's reservation was their over-dependence on pediatric HCPs to provide "a little safety net" (mother of female survivor, 15 years) due to the survivor's lack of self-management skills. Amongst participants with cognitive difficulties who expressed positive transition attitudes (3/8, 37.5%), only one parent did so without reservation: "I'm happy with her PCP, I'm happy with the system" (mother of female survivor, 16 years).

Inadequate communication

Seven participants (7/33, 21%) identified inadequate communication between themselves and their pediatric and future adult HCPs as a barrier to transition, which contributed to participants' negative transition attitudes. Inadequate communication between HCPs led to one participant's PCP only having "the summary letter [given during] transfer…to go by" (male survivor, 20 years). Participants also reported feeling isolated from HCPs due to poor communication, with one participant realizing post-transition "okay, we are actually on our own now" (mother of male survivor, 15 years).

Lack of confidence in primary care physicians

A common barrier to transition was the perception that PCPs did not have sufficient cancer-specific knowledge to provide the level of care that pediatric HCPs could (10/33, 30%). This was associated with negative attitudes towards transitioning to PCPs, with one participant commenting that transition "would be alright if it wasn't a discharge to the PCP…if it was a transition to an adult hospital that would be fine" (female survivor, 36 years). In these cases, participants relied on either their family to take an "extremely central role in [the survivor's] care" (female survivor, 27 years), or themselves to be "the only person who really understood [their] medical history" (male survivor, 31 years).

Discussion

Eighteen survivors and 15 parents of survivors participated in interviews regarding their attitudes towards transition. Barriers included dependence on pediatric HCPs, less confidence in PCPs, inadequate communication, and cognitive difficulty. Enablers included confidence in and proximity to physicians, good communication, information, independence, and older age. A participant's perception of the barriers and enablers of transition appeared to shape their overall attitude towards transition.

A survivor's ability to independently manage their health appeared related to positive attitudes towards transition in our study. Less independent participants were reluctant to transition, fearing losing the familiarity of past HCPs, consistent with lower transition readiness [12]. Some participants expressed that self-management skills could foster independent control of healthcare and transition readiness, consistent with the literature [12, 13]. Other participants proposed that entering the transition process could itself foster self-management skills, suggesting a mutual relationship may exist, where self-management skills aid transition readiness, and transition experience aids the development of self-management skills.

Participants who received sufficient information about their ongoing healthcare reported more positive attitudes towards transition, yet 76% of parents report unmet information needs [34]. Consistent with other studies, many survivors (80%) and parents (71%) report needing further personalized information [35, 36]. Participants suggested earlier provision of information (e.g., at diagnosis) could overcome unmet information needs, consistent with previous research [35]. Whilst our participants suggested the Internet as an appropriate medium for information dissemination, a Swiss study of 319 survivors found this to be the least popular method [36]. Written information and a personal manner were preferred by Swiss survivors possibly owing to their less dispersed nature and access to specialized care compared with Australians [36].

Age was a survivor-level factor which was reported as influencing transition attitudes. Similar to the views of pediatric oncologists [22], participants used age to gauge their developmental maturity and indicate transition readiness. A participant's older age signified greater maturity and willingness for specialized adult-focused care, leading to more positive attitudes towards transition. Previous research suggests 87% of survivors over 16 years of age are willing to transition, and 58% of them rate comprehensive adult care as very important to promoting transition readiness [29, 37].

Our results show that cognitive difficulty may be a barrier to transition at the survivor level, reflected in pediatric oncologists' opinions [22]. Consistent with past research [7, 12, 38], participants suggested that cognitive difficulty hindered the development of self-management skills, which could lead to over-dependence on parents or past physicians. Participants also indicated that cognitive difficulties could limit survivors' ability to process information relevant to transition, making self-management skills (e.g., remembering/retelling their medical history) difficult [11]. Past research with survivors with cognitive difficulties found common areas of deficit included poor executive function and attention and concentration [39]. Our participants recommended a slower transition process to combat this, where the concept of transition was introduced early and discussed often to facilitate leaving pediatric-focused survivor care.

At the healthcare system level, inadequate communication between HCPs resulted in participants having to repeatedly retell their medical history and depend on past HCPs for support. Sub-optimal communication between past and future HCPs has been shown to impede transition [40]. Participants suggested meetings between those involved in the transition process to combat this, which was echoed in a recent study of LTFU experts [23]. This suggests that a community-based shared-care model, where the PCP coordinates with different sub-specialties, may be an effective solution to the barrier of communication [23, 41]. Review of Survivorship Care Plans to ensure transfer of data and recommendations for future surveillance could overcome some communication issues.

Engaging with PCPs was a barrier to transition when survivors lacked confidence in their ability to provide survivorship care, influencing negative transition attitudes. Suh et al. [21] and Lawrence et al. [42] have shown PCPs exhibit reduced awareness of survivor-related healthcare issues. Interventions such as transitional education of PCPs, early introduction of co-management of survivors by PCPs and oncologists, and web-based information dissemination may foster familiarity and confidence in PCPs [21]. Engaging with PCPs who were located closer to survivors than distant previous HCPs was an enabler of transition, appearing to influence positive transition attitudes. Transportation and time are barriers that commonly burden survivors and their caregivers [43, 44].

A potential limitation of this study was that transition status was determined from participants' self-report, limiting a valid assessment of the appropriateness of such transition. Although the sample size was small, we reached thematic saturation (assessed alongside data collection) to ensure a broad sample of perspectives achieved by recruiting survivors/parents across ANZ. Our findings may be applicable beyond ANZ, as barriers/enablers identified in our study are modifiable in any context to ensure optimal care. This study's qualitative approach allowed for a nuanced experiential perspective of an understudied area. However, its cross-sectional design limits causal relationships being drawn from inferred themes. Current interventions target the development of easily modifiable self-management skills before transition [12, 13, 45]. However, further research is required to clarify our finding that entry into transition could promote the development of self-management skills. Future research into the information needs of survivors should determine whether survivors with cognitive difficulties have higher rates of unmet information needs than survivors without cognitive difficulties.

Over a half of participants expressed overall positive attitudes towards transition, whilst under a third reported negative attitudes. Barriers to transition included dependence on pediatric HCPs, low confidence in PCPs, inadequate communication, and cognitive difficulty. Addressing these barriers may improve satisfaction with care and engagement in follow-up. This includes introducing transition earlier to families, encouraging HCP collaboration/communication, and better information provision. Future studies that appreciate the experiential perspective of survivors and their families as they transition from pediatric to adult healthcare are required to fully understand the barriers of transition.

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Compliance with ethical standards

Ethics approval was obtained from all participating hospitals, and informed consent was obtained from all participants before proceeding with the study.

Conflicts of interest statement The authors declare that they have no conflict of interest.

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