

# Psychological factors impacting transition from paediatric to adult care by childhood cancer survivors

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## Abstract

**Purpose** Childhood cancer survivors require life-long care focused on the specific late effects that may arise from their cancer and its treatment. In many centers, survivors are required to transition from follow-up care in a paediatric cancer center, to care provided in an adult care setting. The purpose of this study was to identify the psychological factors involved in this transition to adult care long-term follow-up clinics.

**Methods** Qualitative interviews were conducted with ten paediatric survivors still in paediatric care, as well as 28 adult survivors of whom 11 had transitioned successfully to adult care (attended three long-term follow-up (LTFU) appointments consecutively); ten who failed to transition (attended at least one LTFU appointment as an adult, but were inconsistent with subsequent attendance); and seven who had never transitioned (did not attend any LTFU care as an adult). Line-by-line coding was used to establish categories and themes. Constant comparison was used to examine relationships within and across codes and categories.

**Results** Two overall categories and four subthemes were identified: (1) *Identification with being a cancer survivor* included the subthemes of 'cancer identity' and 'cancer a thing of the past' and; (2) *Emotional components* included the subthemes of 'fear and anxiety' and 'gratitude and gaining perspective'. The analysis revealed that the same factor could act as either a motivator or a hindrance to successful transition in different survivors (e.g., fear of recurrence of cancer might be a barrier or a facilitator depending on the survivor's life experience).

**Conclusions** Psychological factors are an important consideration when preparing cancer survivors for transition to adult long-term follow-up care. Identifying and addressing the individual psychological needs of childhood cancer survivors may improve the likelihood of their successful transition to adult care.

**Keywords** Long-term follow-up care · Cancer survivor · Adolescents · Qualitative research

## Introduction

Childhood cancer survivors and their risk for late effects

More than 80 % of children diagnosed with childhood cancer will survive their disease [1, 2]. Consequently, the population of childhood cancer survivors has grown — there are more than 325,000 survivors of childhood cancer alive in the United States of America (USA) [3], and approximately 36,000 survivors in Canada. Much of the improvement in survival has been achieved through the use of multimodality therapies that included a combination of surgery, chemotherapy, radiation and hematopoietic stem cell transplantation. These therapies place many survivors at considerable risk for long-term morbidity and early mortality [4–7].

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The risk for health problems can be reduced by early detection or prevention strategies. As such, the US Institute of Medicine (IOM) has recommended lifelong ‘risk-based’ health care for all cancer survivors [8]. Despite the publication of guidelines advocating regular medical visits and periodic surveillance tests focused on preventing or detecting these adverse late effects of therapy [9–11], only a small number of adult survivors of childhood cancer receive regular health care that is tailored to the risks arising from their cancer treatment [12, 13].

#### Medical care of survivors of childhood cancer

Most childhood cancer survivors receive regular long-term follow-up (LTFU) care in a cancer center during their childhood years [13]. In the USA, the majority of paediatric cancer institutions have a specialized LTFU program that delivers risk-based health care to survivors during their childhood years [13–15]. However, many of these institutions do not have clinics that can care for these survivors once they become adults, and thus, these patients are often transferred to their primary care physician for LTFU care [13]. Even when specialized clinics for adult survivors exist, insurance limitations, travel distances and other barriers may lead to loss of attendance at follow-up appointments over time [16].

In Canada, 12 of the 17 (71 %) paediatric cancer centers have a formal program or clinic dedicated to the long-term follow-up care of survivors during their paediatric and adolescent years, while the remainder continue to care for survivors in their acute care oncology clinics [13]. The majority of adult survivors of childhood cancer in Canada report receiving care from a family physician and not from a cancer center-based specialist [17]. In Ontario, the province’s five paediatric cancer centers is linked to a specialized clinic that provides lifelong care to survivors of childhood cancer once they enter adulthood. In three of these centers, paediatric and adult long-term follow-up clinics are combined such that survivors stay in a single clinic for life. The other two centers transfer adult survivors from a long-term follow-up clinic in a paediatric hospital to a separate survivor clinic housed in an adult cancer center. Despite this integrated system for survivor care in Ontario, many adult survivors are lost to follow-up at the time of transition, and many drop out of follow-up in the years following transition.

#### Studies of barriers to transition in paediatric populations with chronic illness

Of the research that has assessed transition barriers in *other* chronic paediatric illnesses (e.g., diabetes, spina bifida and cystic fibrosis), numerous individual and health care system barriers to transition from the patient, parent and health care provider perspectives have been identified [18]. Individual barriers identified for adolescents include issues around

their level of maturity, readiness to assume responsibility for their own healthcare and lack of knowledge of their health condition and its implications [19, 20]. Adolescents have also reported poor preparation for transition, limited educational materials and counselling, and a concern about provider’s levels of competency as barriers [21–25].

Despite the available access to appropriate LTFU care in the Province of Ontario, many young adult survivors fail to transition from paediatric to adult care, or drop out of care after transitioning successfully. The purpose of this analysis, which was part of a larger study examining the barriers and facilitators of transition to adult care, was to identify the psychological factors involved in the transition of childhood cancer survivors to adult health care facilities in order to inform development and testing of interventions that can potentially improve successful transition and reduce attrition.

## Methods

### Study design and participants

We used a constructivist grounded theory approach [26]. A purposive sample of 38 childhood cancer survivors was interviewed between September 2010 and October 2011 (see Table 1 for participant demographics). Participants were recruited from two major paediatric cancer hospitals which represent the two different models of LTFU care within the centralized Ontario system, the Hospital for Sick

**Table 1** Participant demographics

Characteristic	N=38 (%)
Current age	Mean=21 (R=15–26)
Age at diagnosis	R=3 months–17 years
0–7	26
8–12	9
13–18	3
Female	15 (39)
Male	23 (61)
Transition phase	
Pretransition	10 (26)
Successful transitioned	11 (29)
Failed to transition	10 (26)
Never transition	7 (18)
Cancer type	
Leukemia	14 (37)
Lymphoma	6 (16)
Neuroblastoma	5 (13)
Wilm’s tumour	5 (13)
Sarcoma	4 (11)
Brain tumour	4 (11)

Children and McMaster Children's Hospital (see Fig. 1). Survivors at McMaster Children's Hospital remain in the same LTFU clinic during both childhood and adulthood and are cared for by a common team. The clinic is staffed by oncologists, nurses and nurse practitioners, social workers, clinical pharmacists, child life specialists, physiotherapists, occupational therapists, nutritionists and psychologists. In contrast, the LTFU program at the Hospital for Sick Children formally transitions survivors to an adult LTFU clinic located in Princess Margaret Hospital at age 18, and thus, survivors were recruited from Princess Margaret Hospital as well.

The long-term follow-up clinic is responsible for all the coordination of after care for patients and makes referrals to relevant specialists. These clinics are responsible for the risk-based surveillance based on the oncology treatment history of the patient. The clinical staff is trained to identify

late effects associated with childhood cancer and its treatment, and to promote lifestyle and health behaviours to promote continued health. While patients may also attend specialist clinics (e.g., cardiac, fertility, pulmonary specialists, etc.) if necessary, LTFU is an important and unique health care service designed specifically for childhood cancer survivors. We recruited participants who were preparing to transition, participants who had transitioned successfully, and participants who failed to transition, or never had transitioned (see Table 2 for eligibility criteria definitions) to the LTFU clinics. Youth between the ages of 15–17 years were defined as pretransition because the policy is to transfer patients to adult care at the age of 18 years and preparation to transition to adult care begins around the age of 15 years. In the case of the Hospital for Sick Children, this transition means moving to a Princess Margaret Hospital while at

**Fig. 1** LTFU care models at The Hospital for Sick Children and at McMaster Children's Hospital

LTFU Model 1 – Paediatric and adult LTFU Care Provided in a Common Clinic

McMaster Children's Hospital

- Specialized LTFU clinic for paediatric **and** adult survivors of childhood cancer
- Annual/biennial visits
- Staffed by oncologists, paediatric nurses and nurse practitioners, paediatricians, social workers, clinical pharmacists, child life specialists, physiotherapists, occupational therapists, nutritionists and psychologists.
- Referred to specialists as needed
- Life long care

LTFU Model 2 - Transition from LTFU clinic in a paediatric hospital to LTFU clinic in an adult hospital

Hospital for Sick Children

Princess Margaret Hospital

- Specialized LTFU clinic
- Annual visits
- Entry at least 4 years after diagnosis and 2 years off active treatment
- Staffed by paediatric oncologists, paediatrician, dietician, clinical psychologist, neuropsychologist, nurse and paediatric endocrinologist.
- Referred to specialists as needed

Transition at age 18

- Specialized LTFU clinic for adult survivors of childhood cancer
- Annual/biennial visits
- Staffed by radiation oncologists, nurse, social worker, neuropsychologist, clinical psychologist
- Referrals to specialists as needed
- Lifelong care

**Table 2** Definitions of transition

Term	Definition
Pretransition	An adolescent childhood cancer survivor who attends LTFU care at a paediatric centre and has yet to transition to adult care.
Successful transition	An adult childhood cancer survivor who attends (frequencies may vary but as directed by oncologist) LTFU for a continuous period of 3 years.
Never transitioned	An adult childhood cancer survivor who never attends a LTFU appointment in an adult centre.
Failed to transition	An adult childhood cancer survivor who attends at least one appointment as an adult but fails to attend LTFU (frequencies may vary but as directed by oncologist) for continuous period of 3 years.

McMaster Children's Hospital, LTFU occurs in the same center. Successful transition was defined as attending three consecutive follow-up appointments in the aftercare clinic in order to ensure that the patients were consistently engaging with the medical care system as adults and not dropping out of follow-up care prematurely. Survivors who were unable to speak or understand English, or who had severe cognitive impairment that would limit participation in a qualitative interview were not eligible for this study.

### Procedures

Research ethics board approval was obtained from each hospital prior to beginning the study. Eligible survivors were identified by review of each institution's clinic database. Eligibility was confirmed by review of potential participants' medical records. Eligible survivors were either approached in the LTFU clinic by a member of their clinical team, or contacted by a letter explaining the study. Letters included a prepaid reply postcard asking them to indicate their interest in the study. Nonrespondents were contacted by a phone call 2 weeks later to confirm that they had received the information. The research team was notified of any interested participants who were then contacted by telephone to schedule a time and location for an interview.

Interviews were conducted by experienced qualitative researchers in the hospital, survivors' homes, or over the telephone. Informed consent and participants' agreement to the interview being audio-recorded was obtained at the beginning of each interview. We used a semistructured interview guide with questions designed to encourage participants to discuss their feelings and experiences in-depth. All interviews were recorded digitally and transcribed verbatim with all patient identifiers removed from the transcripts.

### Data collection and analysis

Interviews began with asking the participant to tell the story of their childhood cancer diagnosis. Questions and probes were designed to encourage participants to discuss their feelings and experiences about their diagnosis and treatment. We

further probed for survivors' perceptions of barriers and facilitators to transition from paediatric to adult care and components that are involved in the transition process. Our team closely followed the method for coding and analyzing qualitative data as outlined by Charmaz [26]. Data collection and analysis took place concurrently, which allowed the researchers to revise the interview guide regularly to gather data to refine emerging codes (see Appendix for sample questions). Analysis was inductive and involved line-by-line coding, with codes and categories emerging from participants' stories. The first ten transcripts were coded separately by the team members, followed by several team discussions on the developing coding scheme to ensure consistency between coders. Focused and theoretical coding was used to sift through large amounts of data and to strengthen initial codes. Constant comparison was used to examine relationships within and across codes and categories. Interviewing continued until no new codes or themes emerged. QSR NVivo 8 software was used to manage the data [27].

### Results

As noted in the introduction, the findings from this study were part of a larger research project exploring facilitators and barriers to transition to adult health care. Participants reported on a range of factors that acted as facilitators or barriers to transition including health care system factors; survivors' knowledge of their disease, treatments and late effects; severity of late effects; type of cancer; and psychological and social factors as related to transition. In this manuscript, we describe in detail the psychological factors related to transition and report on the other factors in a forthcoming paper. While social factors are sometimes considered part of the psychological domain, we exclude them in this report in favour of focusing on the *intrapersonal* components associated with transition that include identity and affect. The *interpersonal* components including both instrumental and social support from family and friends is reported in another manuscript.

Participants talked about a range of psychological issues when it came to transition to adult care. While participants

were probed about whether these factors were barriers or facilitators in the transition process, our research revealed that the same factor could be a motivator or a hindrance to successful transition in different survivors (e.g., fear of recurrence of cancer can act as a barrier or facilitator depending on the survivor's background and life experience). In the findings, we outline the psychological factors involved in transition to adult care and situate them within the context of barriers and facilitators to successful transition as reported by our participants. These included: (1) *Identification with being a cancer survivor* that included the related subthemes of 'cancer identity' and 'cancer a thing of the past' and; (2) *Emotional components* including the subthemes of 'fear and anxiety' and 'gratitude and gaining perspective'.

#### Identification with being a cancer survivor

Under the category of identification with being a cancer survivor, two related subthemes emerged. The first subtheme relates to the degree to which participants identified themselves as having a 'cancer identity' or how much they felt that their cancer history was a part of their current self-understanding. The second subtheme relates to the belief that 'cancer was a thing of the past' and therefore, was a marginal or insignificant part of their histories that they wanted to be put behind them (Table 3).

#### Cancer identity

Participants who identified with having had cancer and who saw themselves as a 'survivor' of the disease were more likely to see cancer as an ongoing part of their lives. These participants tended (although this was not exclusively the case) to be more involved with cancer organizations, such as camps for children with cancer that served cancer patients or survivors, and seemed more likely to attend follow-up care. The ability to integrate a positive cancer identity as part of self-understanding was on the whole, associated with a greater likelihood of successful transition. One successfully transitioned participant talked about her experience at a camp for people who had gone through cancer and noted about her attendance:

12: [attending camp] changed my life a lot. It was just a place where you can meet other kids. Everyone's

**Table 3** Psychological components related to transition to adult care

Category	Identification with being a cancer survivor	Emotional components
Subtheme	Cancer identity	Fear and anxiety
Subtheme	Cancer a thing of the past	Gratitude/having perspective

sick so you didn't really feel different and just could see how resilient people could be.

I: Did you guys talk to each other about your treatment protocols and continuing to seek long-term care?

P: We'd always be like, 'when's your appointment?' kind of thing... but everyone pretty much there, when I was there went for regular checkups and was pretty good about it (age 23, successful).

On the other hand, those who did not identify themselves as cancer survivors seemed less likely to see the importance of transitioning to regular adult care. One participant noted:

22: I felt more like there was no concern, so why was I going? ... And so after university ... I didn't find any concerns with it, so I didn't have any real pull to bring me there, and like I said, I don't view myself so much as a cancer survivor so that's not always on my brain. When something comes up I don't always think, 'oh I should just go for that cancer checkup' or, you know, I should go ... for that aftercare. I think I just don't have that that pull to go there. ... My mentality of a cancer survivor wasn't there (age 24, never transitioned).

#### Cancer a thing of the past

The notion that 'cancer is a thing of the past' had to do with the belief that the cancer diagnosis and trajectory was not a major part of the participants' current life, and further, something *they wanted to actively dismiss and forget as part of their histories*. Not only did these participants refrain from identifying as a cancer survivor, they actively wanted to put it behind them. Sometimes this had to do with the participant's age when they were first diagnosed. The younger a participant was at the time of diagnosis and the better their prognosis at the time of cancer diagnosis, the more likely the participant was to judge cancer being a 'thing of the past' and therefore, not requiring adult health care. One teen who had failed to transition noted:

20: My chemo wasn't even that strong, it's like the cancer that I had it wasn't a serious cancer. It's not like I overcame like a brain tumour or something like that, you know what I'm saying? So, it kind of takes away from what you underwent, it really, it was like a little blip in your life but it's so far away now that it's not going to come back (age 26, failed to transition).

Similarly, another 20-year-old male who did not see the importance of follow-up care and could not connect the cancer experience to this current life explained:

36: I was very young and I don't really remember anything. If it happened, you know, a couple of years



ago then that would have been completely different. I would have been giving you completely different answers, but I mean, since I was so young I don't remember the experience of going through chemo or things like that (age 20, never transitioned).

Lastly, another failed transition participant similarly echoed:

17: It just it was so long ago that you know when I was young, it doesn't it doesn't affect me that much (age 23, never transitioned).

### Emotional components

Under the category emotional components, two subthemes arose in relationship to cancer and transition to adult care. The first had to do with fear and anxiety over one's cancer in the past, and in the future, and the second had to do with gratitude and gaining perspective from having had cancer.

#### *Fear and anxiety*

Fear around cancer was a robust theme in the transcripts. Participants reported fear of cancer recurring; fear of developing a new type of cancer; fear of developing late effects from their cancer treatment; fear of dying of cancer; and fearful memories associated with having had cancer in the past (i.e., memories of being afraid while receiving chemotherapy and/or surgery). As with the complexity of the other findings, for some, fear was a motivator to committing to adult follow-up care, and for others fear was associated with reluctance to seek care. In some instances, fear acted as both a barrier and facilitator in the same person. One failed-to-transition participant who had gone to some follow-up care and then stopped attending noted:

15: For the first little while, for sure, I was still really nervous about: is it going to relapse? They say, I think it's up to the first 5 years is risky, the next seven is almost cured, and after ten is considered cured or something like that.

*I: So how many years did you find that 'oh this is worth me coming?'*

P: Definitely the first, I think 5 years, I was still kind of a little bit nervous that maybe it would sneak up on me again (age 26, failed to transition).

This participant noted that fear of cancer was both a motivator and a barrier for her when it came to follow-up care. On the one hand, she explained that she stopped coming because she was less worried about recurrence of cancer as is illustrated in the quote above, but as the interview continued, she also described a kind of inevitability

about a cancer recurrence, and a desire to avoid that worry by not thinking about it 'too much'. She further explained:

15: I try not to think about it too much, I guess, but there's always like a little worry... if I notice a freckle or something. I'm like, 'okay well is that...?'... You know if I'm checking for lumps, or I think it's just because I'm scared of the fact that some chemos can cause other types of cancer. ...It's kind of like what's going to happen? I kind of feel deep down that something like a cancer will come back. It's just kind of a waiting game (age 26, failed to transition).

For another pretransitioned participant, fear was one of the main motivators to attend follow-up care. He reported:

10: I think it's [follow-up care] pretty necessary, like just in case... I know there's still probably a chance that it could come back, so I don't want to risk that by like not going once per year (age 16, pretransition).

#### *Gratitude/having perspective*

While fear was a part of the psychological residue of having had a diagnosis of cancer in the past, participants also spoke about having gratitude for being alive and having developed a maturity and perspective from their cancer experience which was associated with a sense of responsibility about attending follow-up care.

One pretransitioned teen who appeared committed to attending follow-up care talked about the importance of looking after her health with follow-up as part of that routine. Due to her experience, she felt she would not take her health for granted or put herself in other types of risky situations. She explained:

23: It's [cancer] helped me to become a stronger leader in my community and just see things in a different perspective than everyone else. I know that other people take things more for granted than what I do. I wouldn't jeopardize my health by getting into drugs or drinking or risking anything by becoming sexually active or anything. I think it's because, I've seen things differently than everyone else, and I've been put in positions where I have to make big decisions. I know I didn't make them, but like with my amputation and stuff, they said if I didn't have it amputated it could have spread. So, I've seen things a lot differently than everyone else and I think that it's just made me stronger and more aware of everything around me. (age 15, pretransition)

A successfully transitioned young man similarly made the connection between having gratitude for being alive and

not taking his health for granted. For him, attending follow-up care was part of his health care routine. He explained:

9: I guess you could say life, you know you don't take life for granted. ... You had cancer, it's not a choice, it just kind of you know one day you've got it. And okay, well chances are you got good cancer, well, there is no good cancer, but you could have a good chance of surviving, you've got a bad chance of surviving. If you've got a bad chance of surviving and there's nothing they can do for you well you've just got to sit there and die you know it's kind of terrible to think about it like that but it's how it is.

*I: Yeah, so this has given you some perspective it sounds like on the value of life?*

P: I feel you should be healthy. You shouldn't take things for granted (age 21, successful transition).

On the other hand, those who did not feel the cancer had changed them or affected their outlook on life were less likely to say that cancer had given them perspective and less likely to see the importance of follow-up care. One failed-to-transition participant who did not see the value in follow-up care noted:

32: (laughing) I don't know it means a lot that I survived but other than that I mean, I don't know, I live my life like any other 21-year-old does really.

*I: Do you think it influences your day to day decisions, so are there things that you do because you had cancer or things that you won't do because you had cancer?*

P: No. Not really. I like to look at it as, like, just live your life and have fun doing it, you know what I mean? So not really, no. I can't really say that having cancer has influenced any of my decisions (age 21, never transitioned).

## Discussion

There are several models for the care of adult survivors of childhood cancer. Some programs transition to a primary care practitioner, while others offer life-long care in a specialized survivor clinic. An intermediate model advocates maintaining survivors with high levels of morbidity (e.g. survivors of brain tumours or allogeneic hematopoietic stem cell transplantation) in a specialized survivor program, while discharging survivors with less morbidity or risk to their primary care practitioner [28]. However, even if specialized clinics for adult survivors are created, psychological factors affecting survivors will impact their clinic attendance. Our research revealed that these factors include identification with being a cancer survivor and emotional components such as fear, anxiety, gratitude and gaining perspective.

These psychological factors acted as both facilitators and barriers to transition in different childhood cancer survivors.

### Psychological factors and transition

The psychological impact of being a childhood cancer survivor has been documented in a number of studies. Although many survivors adjust well, there are some who struggle to cope with life after cancer [29–32]. Some research has indicated that survivors can suffer from posttraumatic stress disorders [33–35]. In addition, some childhood cancer survivors are at an increased risk for stress-related mental disorders such as acute stress disorder and adjustment disorders [36]. While these studies suggest that psychological factors may be involved in the transition process, few studies have linked these two components explicitly. One Delphi panel, consisting of 17 health policy experts identified potential psychological barriers such as survivors' fears about discovering another cancer, their desire to 'put the cancer experience behind them' and a fear of finding out 'bad news' [37].

In one of the few published studies looking at transition from the perspective of childhood cancer survivors using qualitative methods, Casillias and colleagues [38] identified three barriers to successful transition in a sample of 27 Latino childhood cancer survivors between the ages of 15–21. The two that were psychological in nature and that are relevant to our research include 'cancer stigma' or the 'concern that, in their peer groups, cancer continues to be viewed as a contagious illness or one that is fatal and incurable' (p. 985), resulting in the conclusion that some of our own participants made that, 'cancer treatment is an event that should be kept in the past and not be part of their current identity' (p. 985). The second barrier they identified was the 'recall of the cancer experience as traumatic for the family'. The participants in the study of Casillias and colleagues [38] avoided talking about survivorship care because they thought it would be difficult for their family members to think about this traumatic time in their pasts. The participants in our study also spoke about fear and anxiety about the past and its relationship to future adulthood care, suggesting that previous negativities around the cancer experience may influence current health care behaviour [38].

Another relevant qualitative study interviewed 12 participants between the ages of 12 and 21 who had received a cancer diagnosis before 18 years of age [39]. Their findings revealed that, as with our study, appreciation and gratitude were part of the experience of having gone through cancer that remained salient after diagnosis and treatment. Moreover, the authors found that young adults were struggling to 'form an identity that included both their cancer and their survivor experience' (p. 1038) and that this identity struggle was challenging for some of them in the context of moving to adult health care [39].

## Implications for practice

One way for health care professionals to identify and address psychological needs of transitioning teens is to incorporate and address these issues as part of the preparation for transition [40]. A paediatric oncologist, or a primary nurse responsible for preparing the teen to transition to adult care, can address these issues by probing specifically about psychological factors. For example, a clinician might engage the transitioning teen in a structured type of clinical interview that would ask questions about any fear or anxiety they may have about cancer recurring. Rather than ask a teen directly if they are ready to transition (which they may answer affirmatively), with a few additional questions that target some of the psychological processes concerned with transition, a health care professional might be better able to address the factors that could potentially be a barrier to successful transition. By addressing these issues in advance of transition, the health care team can identify patients who may need additional help with the transition process and a mental health professional, such as a psychologist, can be called in to assist with the underlying issues that may prove to be a barrier down the line for successful transition.

Another implication for practice is to empower teens' sense of identity with having been a cancer survivor by engaging their peers and encouraging them to attend cancer-related groups and organizations that provide information and social support for survivors (e.g., camps, young adult cancer groups and social outings). Engaging with other teens who identify as cancer survivors in social situations may have an indirect effect on health behaviour and motivation to attend follow-up care. Social contagion theory postulates that good behaviours, such as quitting smoking, maintaining a healthy body weight and positive affect, are 'contagious' and pass from friend to friend within a social network [41]. Health behaviours, therefore, can be influenced by social settings where one can 'pick up' friends' behaviours and emulate them in one's own life [41].

In one study, Christakis and Fowler [42] found that social networks affected health behaviours profoundly. They studied a cohort of 12,068 people assessed multiple times between 1971 and 2003 as part of the Framingham heart study. They examined whether weight gain in one person was associated with weight gain in others in that person's social network that included friends, siblings and spouses. For example, they found that a person's chance of becoming obese increased 57 % if they had a friend who had become obese in the same time interval. The authors noted: 'Friends and siblings of the same sex appeared to have more influence on the weight gain of each other than did pairs of friends and siblings of the opposite sex...it seems likely that people are influenced more by those they resemble than by those they do not' (p. 37).

These findings suggest that social networks are potentially promising places to intervene in order to affect the health care decisions of transitioning teens. Good health behaviours of peers who are also cancer survivors can have a profound impact on survivors' willingness to identify with being a cancer survivor and may also have an impact on good health promotion behaviours such as committing and adhering to follow-up care. In the transition context, improving adherence should involve an immersion with peers of the same age and sex who identify with their cancer survivor status and who follow good health habits. This could be achieved through camps or organizations that involve peers as well as through peer mentor or 'buddy systems' within the health care context.

## Limitations

The main limitation of this study is that it was conducted in the context of a provincial health care system that aims to offer all survivors life-long care in a specialized LTFU clinic. Survivors who receive LTFU care from primary care practitioners or in other medical settings were not interviewed, and therefore some of these findings may not be generalizable to other childhood cancer survivors receiving LTFU care elsewhere. Moreover, Canadians have access to socialized health care and do not need to pay for most of their health care services including LTFU care in the hospital clinics. It is possible that childhood cancer survivors may have different concerns in other countries, such as the USA, where health care may be more costly for the individual patient.

## Conclusion

In a recent report on transition, Harder and Krull [40] stated 'a lack of identification and/or treatment for psychological problems intensifies risk for poor health status and adverse health outcomes in adulthood' (p. 52). The research we reviewed here in the context of this transition study concurs with this statement and suggests that psychological factors are important to take into consideration because health behaviour may not always be rational. It can be affect driven (e.g., fear) and/or motivated by identification with one's childhood cancer survivorship status. By addressing psychological needs of teens transitioning to adult care, there may be better compliance in follow-up care since the underlying motivations and needs of paediatric cancer survivors are being met.

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## Appendix

### Selected questions from the semi-structured interview guide

#### Patient factor

1. Can you tell me about the details of your cancer? (e.g., age at diagnosis; details about type of cancer; stage/risk/relapse)
2. Can you talk about what being a cancer survivor means to you?
3. Can you tell me about your feelings associated with having (had) cancer?
4. Have you had any negative experiences as a result of having had cancer?
5. Are there any things associated with your cancer that you worry about? If so, what kinds of things?
6. Do you identify as being a cancer survivor? If so, what does that identity look like for you? (e.g., participating in cancer groups?; participating in cancer events?)
7. How, if at all, has having had cancer changed your perspective on life?
8. Do any of your experiences in the past make you want to attend or not attend follow-up care?

#### Transition factors

1. Do you see yourself continuing to seek follow-up care?
2. What do you think are some of the benefits of continuing to attend long-term follow-up are?
3. Can you describe some of the things you think will make it difficult for you to continue to see a health care provider about your cancer when you become an adult?
4. Can you describe some of the things you think will help you to continue to see a health care provider about your cancer treatment and possible late effects when you become an adult?
5. What kinds of services (e.g., medical, psychosocial, vocational) do you think will be useful to you as an adult childhood cancer survivor?

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