

“IN REALITY IT MIGHT BE ONE FINGER VERSUS THE WHOLE HAND WHEN THEY TELL YOU STUFF”: UNVEILING PERSPECTIVES OF YOUNG ADULT CHILDHOOD CANCER SURVIVORS

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ABSTRACT

Introduction: As about 82% of children with childhood cancer survive more than 5 years after diagnosis, living as a cancer survivor elicits a new reality that can include psychosocial effects. These impacts interact collectively, especially regarding re-assimilation, and are rarely explored. The purpose of this study is to explore the psychosocial impacts of surviving childhood cancer and re-assimilation back into society in young adult survivors of childhood cancer.

Methods: Individual in-depth semi-structured interviews were conducted with young adult childhood cancer survivors. Questions explored psychosocial aspects associated with returning to work, school, and social environments after remission. Interpretive phenomenological analysis was conducted once interviews were manually transcribed, followed by a group interview to discuss the study's findings.

Results: Four individual interviews were conducted as well as one group interview. Interviews and the group interview revealed 3 major themes: outlook on re-assimilating, outlook on coping, and outlook on cancer. Largely, the lack of preparedness and support seemed to delay the transition process, and this hindered coping and forming connections, resulting in exacerbated positive or negative coping behaviors.

Conclusions: This work is a first step to understanding how survivors' personal outlook on coping and healthcare system barriers played influential roles in re-assimilation. Survivors seem to need reliable survivorship information and improved communication with healthcare providers as to what to expect in order to feel prepared for life post-cancer. Follow-up appointments for patients during and after their treatment specifically to discuss latent effects such as mental health, changes expected in returning to life, and other psychosocial aspects can go a long way and may enhance communication between HCPs and survivors. These aspects need to be deeply understood through other qualitative studies. **Keywords:** childhood cancer; survivorship; re-assimilating; transition; psychosocial impact; young adult

INTRODUCTION

Approximately 82% of children with childhood cancer survive more than five years after diagnosis. Living as a cancer survivor elicits a new reality that can include psychosocial impacts. These psychosocial impacts interact collectively, especially regarding re-assimilation, and are rarely explored.

Re-assimilation is one of the most important challenges faced by young adult cancer survivors and is identified as a priority to address in future survivorship research ¹. There is a link between re-assimilation and the psychosocial impacts of childhood cancer. However, it is not well understood how the context of transitioning from cancer patient to survivor and re-assimilation impacts other aspects of their lives ². The extent to which re-assimilating impacts the trajectory of psychosocial development as children develop into young adults is also unclear.

Assimilation is “the process of receiving new facts, or of responding to new situations in conformity with what is already available to consciousness” ³. Survivors are faced with a new reality (responding to a new situation) following treatment and are faced with having to navigate that reality based on their own perspectives (what is already available to consciousness). Re-assimilation is explored and described as the return to life following cancer treatment, which includes navigating school, work, and social relationships. In this study, it is a type of reintegration into society where cancer survivors re-establish social norms (e.g., friend groups, go back to school/work, or start relationships that previously were difficult due to being sick or on active treatment).

METHODS AND METHODOLOGY

Interpretive phenomenology was applied to understand the transition from childhood cancer patient to survivor, transitioning back into society and dealing with the lasting psychosocial impacts of surviving childhood cancer.

Recruitment was done through Childhood Cancer Survivor Canada. There were a total of 4 Individual in-depth semi-structured interviews conducted virtually and lasted 29 to 63 minutes. Once individual interviews were completed, participants were contacted to participate in a group interview. The group interview involved participants number 2 and 4 and lasted for approximately 60 minutes.

Interpretation occurred at two levels. First, observations were interpreted through the eyes of the participants and how they interpreted their context. The second level was to understand the meaning of the participants' experiences, to provide a rich narrative story of the phenomenon that can communicate why participants felt the way they did ⁴.

RESULTS

Outlook on re-assimilating: the aftermath of cancer, and changes observed within their social environments, “*Perceived ability to re-assimilate*” - P1 stated: That’s where I think a lot of the trauma really happened, because it was like, “Deal with it,” and “life or death,” but then nobody bothered to transition me into normal life, or to help me understand what I’d expect. “*Forming connections,*” - P1 expressed, “A lot of things as a teenager or as a young adult that might seem like really cool, important milestones weren’t quite as important to me.

Outlook on coping: learning to embrace their new reality and sharing inward perspectives on themselves “*Ability to cope*” - P1 shared, “I felt very angry, because not only was my body failing me, it felt like people were failing me, because nobody actually taught me how to cope with it, or how to deal with it, or how to figure out how to get back to where I wanted to be. “*Views on oneself*”:- P4 expressed, There are all these setbacks that are attributed to cancer, but also you don’t want to make that a scapegoat. So, it’s a tough game to play, especially since I’m so far out of cancer treatment, it’s like, is it cancer? Is this an issue of survivorship, or is this me? “*Coping tools*” - P3 shared, Humour. Sarcasm (laughs). That is the number one thing I’d call my main weapon

Outlook on cancer: participants’ experiences with cancer as they were/are facing it. “*Perspective as a patient*” outlined sentiments regarding their experience being hospitalized as a patient and understanding their circumstance. - P2 shared, You develop really strong attachments to the nurses, the social workers, the doctors.. “*The aftermath*” - P4 stated, “Survivor” isn’t really the term at all. It’s more like “victim.” Surviving implies a hard stop and moving on. Whereas I’m still dealing with my diagnosis or repercussions of my diagnosis, which are not seen or appreciated by others in healthcare sectors and it’s frustrating. It’s a lifelong diagnosis for sure.

Participant ID	P1	P2	P3	P4	Mean
Age at diagnosis	13 years	10 years	14 years	16 years	13.25 years
Years into Survivorship	15 years	9 years	11 years	10 years	11.25 years
Diagnosis	Malignant fibrous histiocytoma or spindle cell sarcoma	Acute lymphoblastic leukemia	Stage 3 Hodgkin lymphoma	Stage 4 B Hodgkin lymphoma	
Treatment	Chemotherapy and surgery	Chemotherapy, CART-cell	Chemotherapy and radiation	Chemotherapy, radiation and surgery	
Ethnicity	Caucasian and South American	Caucasian	Middle Eastern	Caucasian	
Gender	Female	Male	Female	Male	
Employment status	Personal trainer	Student	Call center	Student	
Age at interview	29	24	27	26	26.5 years

DISCUSSION

Participant’s personal outlook on coping: Participants’ perspectives on cancer are influenced by their perceived coping ability, which is linked to self-perception and success in their environments. ⁵. Also, feeling ill-equipped, not understanding what to expect, and perceived access to information are indicators for preparedness. Their perceived access to information influences preparedness and survivors are seeking reliability. Largely, the lack of preparedness seems to delay the transition process. This lack can hinder coping and forming connections; it can result in or exacerbate positive or negative coping behaviours and shape the overall outlook of survivorship ⁶.

Barriers to care: During hospitalization, participants had a relatively positive outlook due to the support received from the hospital staff ⁷. Post hospitalization, our participants felt unsupported and unprepared for transitioning. Communication with hospital staff regarding the psychosocial effects such as changes to activities of daily living, fertility concerns, re-connecting with family and peers was lacking ⁸⁻¹¹. In fact, it is relatively unknown how effectively staff communicate the risks of late psychosocial effects to survivors ¹¹. Participants expressed that the support available to survivors is not promoted, maintained, or of good quality, and neglects the holistic experience that is survivorship. There is a greater need for emotional and informational support for survivorship care for childhood cancer survivors. Participants did not feel as though they could ask hospital staff for help, rather relying on staff to raise the topic ¹².

CONCLUSIONS

This study was a starting point to reveal that there was very little to no information communicated to survivors regarding transitioning and the challenges they may face as a result of their cancer experience. There are few supportive resources provided to survivors tailored to assist them in their post-cancer experiences ^{3,10}. This lack of support can be a barrier to effective survivorship care and, ultimately, reduce the ability of childhood cancer survivors to transition post-cancer treatment.

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