

**CANCER AS INTERRUPTION:  
EXPLORING THE EXPERIENCES OF ADOLESCENTS WHO HAVE COMPLETED  
TREATMENT FOR CANCER**

by

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## Abstract

This dissertation provides an interpretive exploration of the experiences of adolescents who have recently completed treatment for cancer. As greater number of adolescents and young adults survive a diagnosis of cancer, their cancer survivorship experiences have become a dominant site of investigation. The conceptualization of cancer survivorship is broad and often encompasses a continuum that begins at the time of treatment completion and extends to years following a cancer diagnosis. The focus of this study is on a phase within this trajectory referred to within this dissertation as posttreatment: a period of time 0-18 months following the cessation of cancer treatment. Posttreatment as a period of time is often invisible and not well understood by patients, their families, or oncology clinicians caring for them. This research was designed to deepen understanding of adolescents' experiences of posttreatment beyond how they are currently constituted in extant research. Using applied hermeneutics as a methodological approach, and specifically Gadamer's dialogical philosophy of hermeneutics, data were generated with thirteen Canadian youth interviewed who had been diagnosed with a variety of cancers and who had completed treatment prior to 18 months from their study participation. The study findings encourage a move away from the essentialized nature that currently conceptualizes posttreatment and offers different ways to understand posttreatment experiences as lived by adolescents. Many of the participants experienced posttreatment as a dynamic and displacing period of time. Specifically, this research suggests that posttreatment is also experienced as embodied, as a liminal space, and a time of shifting relational connectedness for adolescents. By illuminating these diverse and different aspects to posttreatment, this research demonstrates that this period of time is rich in meaning and has many aspects to be understood with new encounters with this topic.

## **Lay Summary**

Adolescents are recognized as a unique group of cancer patients. As the success in cancer treatment continues to grow, many adolescents are surviving a cancer diagnosis and completing cancer treatment. However, ending treatment introduces new challenges for adolescents and is experienced by many as a complex and difficult period of time. Posttreatment as a unique period of time for adolescents is not well understood either within research or in clinical practice. This study offers new exploration of the experiences of posttreatment as it is lived by adolescents who have completed treatment for cancer. The findings of this study show that posttreatment is a period of time that contains diverse experiences for adolescents that includes: confrontation with their changed bodies, feeling caught between having cancer and not having cancer, and experiencing shifting social relationships with those around them. This study invites consideration that adolescents may have distinct needs during posttreatment.

## **Preface**

This dissertation is an original intellectual product of the author, A. Johnson.

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## Acknowledgements

### The Will to Survive

What's it like to have your life change in a moment,  
 what's it like to have it all taken away.  
 Put in the hands of doctors that you just met  
 and just rely on hope to keep you holding on.  
 Here's a story of a journey,  
 one so hard it drains your spirit.  
 So hard to convince yourself that you can make it through.  
 Here's to the fight.  
 Here's to the fighters.  
 Here's to the brave that take this on.  
 Here's to the lost souls.  
 Here's to the new hope.  
 We'll keep on keeping on  
 In the fight for life.  
 The fight for life.

Megan McNeil (1990-2011)

It seems fitting to begin this acknowledgement where the idea of this dissertation began. The above lyrics are part of a song written by the first adolescent with cancer I cared for within my social work practice in pediatric oncology. Megan was strong, determined, open, and light-hearted, and she taught me how to provide therapeutic care to people her age diagnosed with cancer. Over a decade of clinical practice in pediatric oncology later, I have been privileged to come to know many adolescents in this context: many who have survived their cancer diagnosis and many who have not. Many former adolescent patients have travelled with me in spirit through this dissertation journey and I hope that they would find this work meaningful.

The path towards this dissertation has been circuitous: I am grateful to my supervisor and dissertation committee for travelling this path with me. I am thankful to my supervisor, Dr. Grant Charles, who provided consistent support, encouragement, and trust in my ideas. He immediately understood and accepted the significance to me of the topic of this dissertation research and did not sway me away from it. I have appreciated his strong belief that this research matters and this

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There are numerous others and family and friends that have all impacted my dissertation journey positively and I am grateful for their love and support. “It takes a village to raise a child” but it definitely takes a village to raise a child and complete a dissertation. Thank you for being part of my village.

Finally, to the adolescents who participated in this research: thank you for their openness, candour, and honesty. Many expressed their hope that their experiences contribute to greater understanding the impact of posttreatment on people their age and I hope that they would believe that this work contributes to that.

## **Dedication**

To Kai:

I hope one day you believe that  
this work was worth the hours away from you:

“No more work Mommy!”

*We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph.*

Elie Wiesel (n.d.)

## **Chapter One: Introduction**

This dissertation, and the ideas woven through this dissertation, have grown out of my clinical practice, and my deep fondness for, working with adolescents diagnosed with cancer. This dissertation research is centred around understanding the experiences of the posttreatment experiences of adolescents after they have recently completed treatment for cancer. Posttreatment as a defined period is not currently perceived as a distinct period of time within the cancer trajectory following the end of treatment. Posttreatment experiences then are not well understood and the established understanding of how this time is lived by adolescents, is eclipsed by certain dominant paradigms.

The limited understanding of a posttreatment period of time has implications for clinical practice with adolescents as the posttreatment population continues to grow. Cancer survivors have multiple medical and psychosocial needs that often are not adequately met or addressed (Grunfeld & Earle, 2010; McMurtry & Bultz, 2005). Broadly, over the past two decades, advances in the diagnosis and treatment of cancer have enabled people to live longer with a cancer diagnosis in comparison to previous periods of time. This has meant that more people are surviving a diagnosis of cancer and living beyond their cancer treatment. Although the rate of improvement in survival outcomes for adolescents and young adults (AYAs) with cancer has been slower than in other age groups (Bleyer, 2011; Keegan et al, 2016a; Trama et al, 2018), most adolescents treated for cancer are surviving their disease and are transitioning to a posttreatment period of time. With continued advances in diagnosis, efficacy of treatment, and the supportive care for adolescents, likely even greater numbers of adolescents will transition through to posttreatment.

I have titled this dissertation: *Cancer as Interruption*. A diagnosis of cancer for an adolescent is an interruption: of typical development, an interruption of daily life, and an interruption of expectation. The characterization of a cancer diagnosis as an interruption is often implicitly suggested as an explanation as to why the experiences of adolescent and young adults differ from those of younger children or older adults (Patterson et al., 2015): that the meaning of the interruptions created by a cancer diagnosis varies developmentally. It is widely accepted that the developmental period of adolescence and a co-occurring cancer diagnosis, can create a context of significant psychosocial and physical impact. Adolescents have become widely recognized in oncology as a distinct patient population (Albritton & Bleyer, 2003; Barr et al., 2016; Bleyer & Barr, 2007; DePauw et al., 2019; D'Agostino et al., 2011; Fernandez et al., 2011; Sender & Zabokrtsky, 2015; Zebrack et al., 2010; Zebrack & Isaacson, 2012). At the time of a cancer diagnosis, they straddle the worlds of both adolescent and patient and this intersection creates both unique experiences for them as cancer patients and unique challenges caring for them within oncology practice.

My dissertation research is contextualized within this chapter. I discuss what led me to this topic and why the topic of posttreatment is a meaningful portal for greater inquiry. I provide a beginning overview of the understanding of adolescents as a unique group of people diagnosed with cancer and I will take up this consideration more comprehensively in future chapters. Finally, I provide an outline of this dissertation research and offer definitions that have assisted in defining some abstract concepts utilized within this work.

### **Being Addressed by a Topic**

Within philosophical hermeneutics, understanding comes from somewhere. Understanding is not suddenly revealed and its origins are not contained within a strict adherence

to methodological conduct. Instead, understanding is historically enacted: the root of understanding lies within the questions that our previous engagement with a topic directs us to (Gadamer 1960/2004). According to Gadamer, that understanding begins when something addresses us. It is often this experience of being addressed personally by something in our practice heritage that leads researchers in applied disciplines to pursue a hermeneutic approach to research (Moules et al., 2015). An address from a topic is an experience that we were not expecting but one that inspires movement and calls us to action. It also provokes an acknowledgement that we may not have understood an experience in its entirety (Davey, 2006).

The queries surrounding this research study began in the context of pediatric oncology, where, as a social worker, I have had extensive experience working with, and learning from, adolescents diagnosed with cancer. I have had the privilege of working with many adolescents throughout the trajectory of illness- meeting them on their day of diagnosis and seeing them on their last day of treatment. I have been invited into their joys, celebrations, sorrows, and suffering. In particular, I began to see and support many adolescents who had recently completed treatment for cancer. I observed the mediating impact of cancer on adolescents' psychosocial development. I also worked with many adolescents experiencing acute depression, anxiety, psychosocial distress, and suicidality during posttreatment. I began to notice that often these struggles during posttreatment were invisible, not often acknowledged by the adolescent until they were acute, and without an established research base to validate their existence and inform understanding of them, were also not noticed or understood by the clinicians caring for them. I began to realize that this mental health impact was not a rarity but was a common invisible suffering within the systemic response to completing treatment for cancer.

Too often in practice, the celebration of an adolescent completing cancer treatment outweighs potential challenges and complexity within this posttreatment period of time for this group of young people. These observations finally culminated for me in a meeting with an adolescent. This adolescent had completed treatment approximately eight months prior and this meeting was a therapeutic context to explore her emotions and thoughts associated with that. Finally in complete exasperation, she yelled loudly: “*How come no-one understands that recovery is the hardest part of having cancer!*” This was a pivotal turning point for me in my practice and ultimately one that determined my decision to pursue doctoral research. These words reminded me hermeneutically that complex topics can never be truly known and are always at play (Gadamer 1960/1989). I began to understand that I had only partially grasped the meaning of adolescents’ experiences during posttreatment and that this impoverished understanding had significant implications for my clinical practice with them. I began to realize how little I knew about this posttreatment period of time. This adolescent’s words became “turning words” as they began to transform for me my beliefs regarding what is meaningful about the experience of surviving cancer as an adolescent (Davey, 2006).

Over time, I observed significant gaps within both clinician understanding and a systemic response to the posttreatment experiences of adolescents following completion of cancer treatment. These observations further unsettled my understanding and assumptions about surviving cancer. They prompted many reflexive questions about the experiences and perceptions of early posttreatment experiences for adolescents which have fueled the direction of my doctoral work. Throughout my doctoral studies, I resolved to explore the meaning of these early posttreatment experiences, how the construct of posttreatment is currently understood by adolescents, and how adolescents live within a posttreatment period of time. To be addressed by

a topic in philosophical hermeneutics is to both hear and respond to the questions that this call elicits: this dissertation is my response to these questions.

### **Situating Adolescents with Cancer: The Case of Adolescents**

I discuss the physical and psychosocial context of adolescents with cancer in the next chapter. However, here I want to begin to establish the horizon of what is understood about this group of young people diagnosed with cancer. Although I will be speaking in generalities about this population, I briefly want to draw attention back to the opening quote of this dissertation: *we must not see any person as an abstraction*. I have used the word “case” deliberately as the title of this section. The idea of a case, and its contribution to understanding of a phenomenon, is foundational within philosophical hermeneutics which is the approach to understanding that I have utilized for this research. Within this philosophy, a case is a conduit for understanding: it is a carrier of meaning. Unlike more positivist paradigms of understanding, within hermeneutics, understanding is rooted in singularity: a single case (Jardine, 1992). So although the following sections present adolescents as a homogenous group, in this study, adolescents were not perceived as abstracts of the adolescent oncology experience, but rather understood as individual carriers of meaning.

### **AYAs Diagnosed with Cancer**

Cancer remains the biggest cause of disease-related death for adolescents and young adults in high-income countries (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016). In Canada, approximately 2500 adolescents and young adults are diagnosed with cancer each year (Canadian Cancer Society, 2017). A recent report released by the Canadian Cancer Society estimates that almost 2% of cancers will be diagnosed in children and young adults aged 0-29

years (Canadian Cancer Society, 2021). Although a small number of patients, the impact of cancer to this age-group, and the care demands that they require, are significant.

It has only been relatively recently that adolescents have been conceptualized as a distinct group of patients within oncology with different experiences and needs compared to others diagnosed with cancer (Bleyer, 2008). Historically, adolescents have been perceived as both children and adults within oncology but due to collective global efforts, this patient group is now formally recognized as a unique group of patients (Fernandez & Barr, 2006). Within oncology discourse and across health care systems, adolescents are included within a group of patients globally referred to as “AYAs”: “adolescents and young adults”. This is a group of young people that has been formally recognized as a patient cohort that shares a broad spectrum of biomedical and psychosocial vulnerabilities that situates them as different from other groups of people diagnosed with cancer (Albritton & Bleyer, 2003; Barr et al., 2016; Bleyer & Barr, 2007; DePauw et al., 2019; D’Agostino et al., 2011; Fernandez et al., 2011; Sender & Zabokrtsky, 2015; Zebrack et al., 2010; Zebrack & Isaacson, 2012). Although it’s only been the past two decades where increased attention has been directed towards this group of young people in oncology, the origins of the AYA cancer movement began in 1990 with the development of the Teenage Cancer Trust in the UK (Sender & Zabokrtsky, 2015). This group brought attention to the needs of adolescents and young adults as cancer patients and the medical and psychosocial complexity that must be addressed within caring for them.

Initially, the term “AYA” was adopted to foster increased attention towards improving survivorship outcomes for adolescents and young adults. In comparison to both children and older adults, AYAs experienced less improvement in survival outcomes and a lack of progress in survival of this age group (Bleyer et al, 2008). In 2006, the National Cancer Institute (NCI)

convened a scientific meeting to examine the state of research involving this population. Within this meeting, the term “AYA” was born and research and practice efforts to improve their treatment outcomes and quality of life became rooted within the care of this population (Smith et al., 2016).

Internationally, there is no universally accepted age definition of what age range AYA refers to. In Canada, this age range includes those aged 15-29 who have been diagnosed with cancer (Barr et al., 2011; DePauw et al., 2019). In the U.S., this age-range extends to age 39 (Bleyer et al., 2008). The term “AYA” has become a dominant linguistic marker and organizing construct in both oncology practice and research internationally. Although its impetus resides in the noted survival gap in comparison to younger and older patients diagnosed with cancer, its current usage represents an understanding and an acceptance of the distinctness of this patient population and a commitment to research and practice development that will better serve the unique needs of this group of patients.

The term “AYA” has been invaluable in fostering awareness and understanding of a group of patients that have shared experiences and whose experiences are often quite different within the cancer context for both children and older adults. However, the inclusion of both adolescents and young adults within the term AYA does not leave visible what might be unique or different between the experiences of adolescents and young adults. Adolescents and young adults experience different aspects, and degrees of, psychosocial development (Lerner & Steinberg, 2004) and the term AYA has created a population of young people in oncology with little recognized heterogeneity. Although this term has been valuable to foster increased awareness and understanding of the unique needs of this patient group, very little is known about the experiences of adolescents apart from young adults. Their distinctness within the distinct

grouping of AYAs has not been sufficiently addressed within research efforts with this AYA population.

### **Central Problem and Purpose of the Study**

Within this chapter, I have so far outlined the threads that contribute to considering adolescents as a unique population within oncology. I now shift my focus to the specific context of my dissertation research.

### **The Research Problem**

The dominant paradigm for understanding the posttreatment experiences of adolescents who have completed treatment for cancer has been one of psychological and psychosocial distress (Hedstrom et al., 2005; Kwak et al., 2013a). Distress as a paradigm stands relatively unchallenged in this context and is often perceived as an inevitable consequence to being diagnosed with, and treated for, cancer as an adolescent and young adult. Distress has become a foundational construct in cancer survivorship research. Outside of very few exceptions, very little research has been done to understand other aspects of the early posttreatment experiences of adolescents outside of distress. This has resulted in a paucity of knowledge of the experiences of adolescents when they transition from active treatment to completing treatment. My dissertation research broadens the understanding of a posttreatment period of time and creates spaces for the living complexity of this topic to be seen. Posttreatment is a diverse experience that is lived by adolescents and my dissertation research offers different ways of understanding this period of time.

### **Research Aims**

This dissertation is an exploration, or more specifically, a re-exploration of the experiences of “posttreatment” for adolescents diagnosed with cancer. The primary objective of

this study is to bring attention and consideration to aspects of the posttreatment experiences of adolescents that may be hidden or lost within the dominant paradigms surrounding posttreatment. This research is guided and informed by philosophical hermeneutics and specifically draws on the work and writings of Hans George Gadamer (1900-2002). This approach to attending to this topic offers different vantage points and portals to see this topic in different ways and to deepen understanding of it. Specifically, the study aims were:

- 1) to contribute rich descriptions of the experiences of adolescents who have recently treated for cancer
- 2) to interpret the meaning of posttreatment by adolescents diagnosed with cancer

### **Final Thoughts**

Throughout this chapter, I have outlined the horizon within which adolescents with cancer are situated. I have discussed their uniqueness as a patient group within the cancer context. I have also suggested that there is a gap in the established understanding of posttreatment as previous conceptual paradigms and applications have offered a well-intentioned, but reductive stance, to understanding this complex experience. I have used this contextual embeddedness of adolescents diagnosed with cancer as a spring-board to situate my dissertation research.

The experiences during posttreatment are not simply a continuation of challenges experienced during treatment. Instead, they are distinct experiences endemic to a posttreatment period of time. Little is known about a posttreatment period of time, yet anecdotally, adolescent patients experience this time as dynamic and distinct from their treatment experience. George (2020) writes about the responsibility to understand. He writes “The responsibility to understand may thus be grasped as a responsiveness to the possibilities of the situations we find ourselves in.

This responsiveness is directed toward what, initially at least, and often irresolutely, we cannot comprehend about a situation and, accordingly, what we cannot easily calculate about, predict, control or master” (p.3). Although his discussion is grounded within a call for philosophy to be more attentive and responsive to problems facing the social and non-social world, I have felt compelled to take up this responsibility in the context of adolescent oncology. I believe that as the population of adolescents who survive cancer grows, we do bear this responsibility to understand their experiences and their subsequent needs following the ending of treatment.

### **Terminology**

I introduce a few key terms here because they are central to discussing the experiences of the young people represented in this discussion. Thereafter, I primarily use footnotes to clarify my use of particular terms, and where pertinent, provide a rationale.

**Posttreatment** is a term that I have used deliberately throughout this dissertation. I use this term to represent the time period of up to 18 months that I am exploring following the completion of treatment. I also use this term to separate thinking about this period of time distinctly from cancer survivorship. Discourses of cancer survivor and cancer survivorship have dominated the conceptualization of the period of time after treatment ends. Survivorship is a socially constructed term and using a term such as posttreatment offers both clarity regarding the focus of meaning and also offers the opportunity to consider this period of time differently when freed from the discourse of survivorship.

**Survivor/Survivorship** is used to reference a variety of locations within the cancer trajectory (Mullan, 1985; Rowland et al., 2006). I use both cancer survivor and cancer survivorship to locate an experience following the completion of cancer treatment. Although different conceptualizations of cancer survivorship demonstrate the complexity of this period of

time and challenge any rigidity of understanding this experience, for the sake of clarity, I am referring only to the completion of cancer treatment when utilizing these terms.

**Adolescent** is a term I have used throughout this dissertation to represent the period of development between childhood and adulthood. In this dissertation, this term refers to young people ages 13-19. The World Health Organization (WHO) defines an adolescent as ages 10-19 (World Health Organization, 2021) but I have reduced this range to be more in line with how adolescent, the term “adolescent”, is often typically understood within Western Society. I have taken up the term adolescence in Chapter 3 and have explored its different ontological implications there. There are different understandings of adolescence and different terms utilized in reference to this period of human development and proposed transition. However “adolescent” is a widely utilized organized construct in reference to this population and is the term used throughout oncology discourse and practice when speaking of this population. I use the term “adolescent” as opposed to youth to denote a socially constructed but slippery category between childhood and adulthood. I acknowledge the challenge to the term “adolescence” that scholars of youth studies have highlighted and their concerns that this term conjures normative assumptions about this group of young people (Côté, 2014).

### **Organization of the Thesis**

To conclude this introduction, I provide an overview of the organization of the dissertation which is followed by a brief description of each chapter.

Moving on from this Introduction, in **Chapter Two**, I explore and synthesize various literatures that have been applied to understand and make sense of the posttreatment experiences of adolescents. I demonstrate what is known about posttreatment and discuss relevant literature that provides the current body of research that addresses a posttreatment period of time for

adolescents. I discuss the problems and knowledge gaps that my study addresses and how this field of understanding has been shaped by a dominant discourse. Within this chapter, I trace the rise of distress as a dominant discourse applied to this period of time. I suggest that current understanding of posttreatment is a much more complex and dynamic time period than is currently conceptualized.

In **Chapter Three**, I outline various conceptual frameworks that have also contributed to the understanding of the posttreatment experiences of adolescents. These concepts, although not always explicitly acknowledged or recognized within the perception of these posttreatment experiences, I believe have implicitly influenced how adolescents are conceptualized in research and clinical practice activities.

**Chapter Four** provides a discussion of philosophical hermeneutics which is the methodological approach I have used in this study. Hermeneutics is not a method in the way that other qualitative methodologies are. It therefore requires discussion of the core tenets of this philosophy and I have applied them to the topical context of adolescents posttreatment experiences in efforts to provide both a justification and rationale for the selection of considering this topic in this epistemological manner. I have also provided a discussion of how I have applied specific tenets of Gadamerian hermeneutics within the more methodological context of my dissertation research and discussed how I have used these tenets within application of this methodological approach.

In **Chapters Five-Seven**, I offer my findings, my hermeneutic interpretations, on adolescents' posttreatment experiences. Within these chapters, I present rich interpretations of aspects of the lived experiences of adolescents who are experiencing a posttreatment period of time.

Finally, in **Chapter Eight**, I summarize the unique and important contributions of this dissertation. Noting limitations of the study, I highlight the key research results and suggest potential implications of my work for adolescents diagnosed with cancer for practice and for future research.

## **Chapter Two: Background and Literature Review**

### **Introduction**

In this chapter, I contextualize my dissertation research with an overview of how adolescents with cancer have been understood within a posttreatment period of time. I begin with a brief discussion of the perception and conceptualization of AYAs (adolescents and young adults) in oncology as a distinct group of patients and the reasons that have informed this perception of distinctness. I then offer a history of the research of the long-term cancer survivorship of adolescents which I argue has been the origin for exploring the after-treatment experiences of adolescents. Next, I narrow my focus to consider what little information is available about posttreatment experiences and adolescents with cancer.

Within this discussion, I suggest that the posttreatment experiences of adolescents have been defined quite narrowly as a period of time that has predominantly been understood as a time of distress. I consider this construct of “distress” and how it has evolved as a dominant discourse in relation to adolescents diagnosed with cancer. Following the examination of this distress-based research, I move to specifically consider the mental health experiences of adolescents in the general population. Mental health is both explicitly and implicitly suggested within the body of work of adolescents’ posttreatment experiences and I align distress research with what is known about adolescents’ mental health more generally. Finally, I briefly offer two other conceptual frames that have informed how a posttreatment period of time has been understood for adolescents. I then conclude this chapter by reiterating the gaps that this dissertation research begins to address.

Within philosophical hermeneutics, the start of taking up a topic is never the beginning of the topic. Topics taken up in research do not stand alone and isolated from their historical

context. Instead they are read back into their histories and traditions of knowing (Moules et al., 2015). The history of a topic shapes and informs the current understanding of a topic. What follows with this chapter is my understanding of the history of the posttreatment experiences of adolescents.

## **The Context of Adolescents Diagnosed with Cancer**

### **Adolescents as Unique Cancer Patients**

The previous chapter outlined both the demographics of adolescents diagnosed with cancer and also their membership within the “AYA” construct. As I discussed, this categorization has not only highlighted their uniqueness as patients within cancer experiences but it has also blurred their distinctness as adolescents with needs and experiences potentially separate from young adults. However, considering adolescents and young adults as a unique group of cancer patients has generated a robust body of research on AYAs that has examined the pathophysiological and psychosocial vulnerabilities in this population following a diagnosis of cancer. It has been argued elsewhere that the global disease burden is greater on AYAs compared to all other age groups in terms of the number of years affected by cancer despite surviving this disease (Bleyer et al. 2017). The success of current cancer treatment has created a growing population of adolescents who have survived a diagnosis of cancer but who live with significant pathophysiological and psychosocial impact.

### ***Pathophysiological Impact***

Adolescents experience a wide range of pathophysiological vulnerabilities within the diagnosis and treatment of cancer. The incidence of cancer in adolescents and young adults internationally has increased more quickly than cancer in any other age group (Bleyer et al., 2017). AYAs experience a unique distribution of cancers and are diagnosed with a group of

cancers that present in this population with significantly greater prevalence than in other age groups of patients (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016). The most commonly diagnosed cancers in 15-19 year olds are: central nervous system tumours, Hodgkin's and non-Hodgkin's lymphoma, leukemia, melanoma, and testicular cancer (Tricoli et al., 2011). What is notable in this context is that cancers experienced in this age group are believed to have different biologies. The same cancers that occur across the age spectrum create differential impact when diagnosed in AYAs (Bleyer et al, 2008). This has helped contribute to the noted survival gap experienced by adolescents and young adults.

AYAs have experienced a much slower rate of progress in improvement in survival outcomes when compared to both children and older adults (Bleyer, 2005; Shaw et al., 2014). While some progress has been made in survival improvement for AYAs across some individual cancers, there continues to be a lack of improvement in survival rates within other cancers diagnosed in this population (Bleyer, 2011; Keegan et al, 2016a). Other proposed reasons for this slower rate of improvement involve delays in diagnosis often experienced by this population (Bleyer & Barr, 2007) and their lower rate of enrollment in clinical trials when compared to children (Ferrari et al., 2008; Tai et al., 2014).

Following the completion of treatment, many AYAs live with significant threats to health and wellbeing. AYAs are at significant risk for co-morbidities and long-term health problems (Barr et al., 2016). They are at increased risk of developing secondary cancers in comparison to both younger and older groups of patients. AYAs who survive cancer for more than five years have a higher relative risk of second malignancies compared with the general population and have a higher absolute risk of second malignancies compared with younger or older cancer survivors. (Lee et al., 2015). AYAs also have to contend with diverse late effects from their

cancer diagnosis and treatment that can be significant and long-lasting (Mulrooney et al., 2008; Soliman & Agresta, 2008; Spathis et al., 2017; Tai et al., 2012).

### ***Psychosocial Impact***

Adolescents and young adults with cancer are not only vulnerable to the physical and biomedical effects from a cancer diagnosis and treatment discussed above, but they are also understood to be impacted psychosocially from cancer occurring at this developmental time. It is therefore both the physical and psychosocial impact of a cancer diagnosis for AYAs that have positioned them globally as a patient population with unique needs as cancer patients (Bleyer et al., 2017). AYAs in particular have become understood as a population of patients that experiences impact in numerous domains of psychosocial development following a diagnosis of cancer. They are tasked with integrating their developmental psychosocial worlds with a diagnosis of a life-threatening disease and many have suggested that a cancer diagnosis delays and regresses adolescents' psychosocial development (Abrams et al., 2007; Epelman, 2013; Zebrack, 2011). There has been extensive research conducted on the psychosocial experiences of adolescents and young adults following a cancer diagnosis that has demonstrated significant psychosocial impact (Abrams et al., 2007; D'Agostino et al., 2011; Isaacson, 2012; Zebrack, 2011; Zebrack & Isaacson, 2012) and the following sections will briefly discuss some of this research.

**Independence.** Following a cancer diagnosis, adolescents spend significant and lengthy periods of time at home or in hospital. Due to their treatment and compromised immune system, they are often removed from school, peers, and other social contexts (Erickson et al., 2010; Gibson et al., 2005). Due to this imposed treatment context, they spend extensive time with family and rely on parents for daily living tasks and practical support. Many adolescents

experience increased dependence on, and require support from, their parents (Grinyer, 2007; Haase & Phillips, 2004). This can challenge their developing independence that they were engaged in prior to a cancer diagnosis (Yi & Zebrack, 2010; Zebrack & Isaacson, 2012).

Although some adolescents and young adults report complicated relationships with parents after a cancer diagnosis, they also report their parents being their strongest source of support throughout treatment (Haluska et al., 2002; Lewis et al., 2013; Woodgate, 2006).

**Peer Relationships.** A diagnosis of cancer can impact the social relationships that adolescents and young adults engage in outside of their immediate family. In a study conducted by Lewis et al. (2013), AYAs described feeling distanced from peers, difficulty fitting in with a peer group, and felt challenged when establishing new relationships with others. Interestingly, the perception of impact on these social relationships differed between different ages of adolescence but impact on social relationships was noted throughout each phase in adolescence. During adolescence, young people identify more strongly with their peers and spend increasing period of time with them (Hamburg, 1998). A diagnosis of cancer often leaves them isolated from their healthy peers and AYAs often feel different from their peers (Haase & Phillips; 2004; Hokkanen et al., 2004; Zebrack et al., 2007). A cancer diagnosis and treatment for AYAs may also adversely impact dating and intimate relationships as AYAs report that cancer has increased their concerns regarding their ability to attract a partner and to establish intimate or romantic relationships (Kelly & Gibson, 2008). Moules et al. (2018) found that a diagnosis and treatment of cancer has a significant impact on the romantic relationships of AYAs.

**Body Image and Self-Esteem.** The physical impact of cancer treatment- scars, hair loss, weight gain etc. can impact AYAs self-esteem and their comfort socially (Lewis et al., 2013). Many adolescents report impact to their body image due to the significant physical changes that

a diagnosis and treatment introduces (Abrams et al., 2007; Larouche & Chin-Peuckert, 2006). This may also impact self-esteem (Bancroft, 2002; Bolte & Zebrack, 2008; Deitz & Mulrooney, 2011). This negative perception of body image has found to persist beyond the ending of treatment (Larouche & Chin-Peuckert, 2006; Lee et al., 2012). Negative perception of body image has also been found to have an influence on the developing sexual identity of adolescents and young adults (Keegan et al., 2016b; Wettergreen et al., 2016). Within adolescence, there is increased attention to psychosexual identity and enhanced attention to sexual intimacy. Due to low self-esteem and body image concerns expressed by adolescents with cancer, they may avoid or are less likely to establish intimate relationships (Evans et al., 2006; Moules et al., 2017). In research by Moules et al. (2017), adolescents' experiences of sexuality within the context of cancer was explored. A diagnosis of cancer impacted adolescents' sense of their sexuality and sexual identity. Adolescents discussed complex navigation with their sexual identity: losing themselves but experiencing themselves differently, navigating their sexuality within normative expectations, and the mutuality between sexuality and a desired intimate relationship for relational connection.

**Fertility.** Closely related to developing sexuality and romantic relationships is fertility and the future desire to have children. Fertility is an important quality of life issue for AYAs treated for cancer as many cancer therapies carry risks to fertility (Bleyer & Barr, 2007). Fertility and fertility-related challenges have been identified as significant sources of distress and concern for adolescents and young adults diagnosed with cancer (CPAC, 2017; Wettergren et al., 2020). Adolescents and young adults have been found to experience fertility concerns involving dating/partner reactions, health risks, the meaning of infertility for their life and fertility-informed emotions involving distress, feeling overwhelmed, and wishful thinking when

confronted with infertility (Benedict et al., 2016). Oncofertility has become a significant lens of attention within the clinical care of AYAs diagnosed with cancer, but a global standard for this practice area is lacking and not every adolescent and young adult is given information about infertility in advance of their cancer treatment (Quinn et al., 2020).

**Education and Vocation.** Finally, many adolescents experience significant disruption to their school and work lives following a diagnosis of cancer. In addition to feeling socially different at school (Lewis et al., 2013), the extended absences from their education can leave them behind their peers academically. When they do return, many experience treatment-related effects that compromise an academically successful return to school. A study conducted by (Donnan et al., 2015) found that 62% of parents identified some sort of neurological or physical challenge that impacted their child or adolescent's return to school. These included: attention, concentration, hearing, fine motor skills, and mobility. Parents also perceived that schools were not providing the necessary support to facilitate a successful return and reintegration back into the academic and social educational environment. Sisk et al. (2020) found that 54% of adolescents and young adult diagnosed with cancer had not returned to school by twelve months following their diagnosis and 39% had not returned to their employment at this time point. Extended school absences and the cancer treatment itself creates educational and vocational challenges that can impede the academic ability and success of this group of young people following the completion of cancer treatment.

### **Systemic Challenges to Caring for Adolescents**

There has been widespread acknowledgement that adolescents and young adults are not best-served by current models of care (DePauw et al., 2019; Fernandez et al., 2011; Ramphal et al., 2016; Ferrari et al., 2021). In addition to the pathophysiological and psychosocial aspects to

their cancer experience just discussed, they are also treated in health care systems designed for both children and adults and therefore do not consistently address their unique medical and psychosocial needs (Bleyer & Barr, 2007; Sender & Zabokrtsky, 2015). Fernandez et al. (2011) refer to this population as the lost tribe: a group of patients that sit between pediatric and adult oncology systems of care as neither system is prepared to meet the diverse needs of adolescents and young adults.

Globally, there have been concerted and focused efforts to advance, develop, and implement cancer care for adolescents and young adults that both acknowledge and integrate their unique medical and psychosocial needs. In 2006, the U.S.-based Adolescent and Young Adult Oncology Progress Review Group released a report titled *Closing the gap: Research and care imperatives for adolescents and young adults with cancer* which formalized attention to the oncology care needs of AYAs (NCI, 2006). In Canada, the Canadian Taskforce of Adolescents and Young Adults was developed in 2008 in order to bring together diverse stakeholders involved with AYAs. This taskforce was funded by the Canadian Partnership Against Cancer (CPAC) and had the goal to improve outcomes and the quality of life of AYAs diagnosed with cancer in Canada. The end of this Taskforce resulted in a report entitled *Adolescents and Young Adults with Cancer* which provided a system performance report for Canada regarding AYA care. Areas identified to advance the care of AYAs in Canada included: incidence and survival, palliation, psychosocial issues, survivorship, and research, including available clinical trials (CPAC, 2017). These have been translated to recommendations and the development of system performance parameters for AYA oncology care (DePauw et al., 2019; Rae et al., 2020).

Within this section, I have offered a brief overview of the pathophysiological, psychosocial, and systemic aspects of being treated for cancer as an adolescent. I now narrow the

focus from this broad context to a historically-situated review of how the experiences of adolescents treated for cancer have been conceptualized and understood.

### **Historical Context of Adolescents and Cancer Survivorship**

My dissertation research explores a posttreatment period of time as lived by adolescents who have completed treatment for cancer. As I will discuss in a following section of this chapter, posttreatment is a relatively new construct within cancer research and practice discourse and so I start this overview with its historical origins in cancer survivorship. “Cancer survivorship” has historically been a dominant organizing construct of posttreatment and therefore warrants consideration regarding how posttreatment is conceptualized and understood. Cancer survivorship is often invoked within the discussion and perception of after-treatment experiences and a review of relevant research in the following sections will situate posttreatment literature.

#### **Cancer Survivorship**

Cancer survivorship as an area of oncology practice and clinician attention has a very recent history (Rowland et al., 2006). The concept and formalized practice of adult cancer survivorship began to take root through advocacy efforts from the American National Coalition for Cancer Survivorship (NCCS) created in 1986. This coalition included representatives from 20 organizations that sought to shift the social perception of a cancer victim to a cancer survivor (Morgan, 2009). Their efforts led to a more formalized concept of “survivorship” and this period of time was understood as a distinct phase in the cancer trajectory where those treated for cancer had different health and wellbeing needs as compared to patients currently receiving treatment and to people without a history of cancer.

As more people lived beyond a cancer diagnosis, the concept of cancer survivorship continued to evolve. A number of activities have helped develop the understanding of cancer

survivorship in adult and child patients and to identify their needs following the end of treatment. In the United States, the Office of Cancer Survivorship at the National Cancer Institute (NCI) was established in 1996 to develop and advocate cancer survivorship research and practice (Rowland et al., 2006). In 2005, the Children's Oncology Group (COG) published guidelines for the comprehensive follow-up guidelines for children (adolescents included) treated for cancer (Meadows, 2006). In Canada, the Canadian Partnership Against Cancer (CPAC) published a report on cancer survivorship, *Advances in survivorship care: Resources and lessons learned, and promising practices* (CPAC, 2012). This report outlined identified "best practice" for survivorship care.

The understanding of cancer survivorship, and the needs of those who have completed treatment for cancer, has historically evolved within a biomedical framework that has focused on medical effects from cancer diagnoses and treatments. Cancer survivorship has been historically rooted in the body- and on the long-term impact on the body from a cancer diagnosis and treatment. Although the physical effects from cancer were identified as central within survivorship care, attention to the psychosocial impact of a cancer diagnosis was a slower development. Meadows (2006) argues that pediatric oncology has advanced cancer survivorship as a field of practice that incorporates both biomedical and psychosocial attention. Not only are chronic and medical late effects assessed and monitored, but there is a collective recognition that being free of cancer is not just being free of the physical effects from cancer: it also involves achieving a good quality of life following cancer treatment. Within this pediatric context, children as cancer survivor were among the first subjects of cancer survivorship research (Meadows, 2006). Survivors of childhood cancer were found to experience a range of medical and psychosocial challenges to their long-term psychosocial functioning and to have many

unique needs that are not well understood as cancer survivors. Of specific interest to my research, is how the psychosocial experiences of adolescents treated for childhood cancer were understood.

### **Adolescents as Cancer Survivors**

With attention towards cancer survivorship care beginning to be established in pediatrics, the psychosocial outcomes of surviving cancer for children was also beginning to be investigated. Historically, adolescents have been considered both as child or adult patients: they were not recognized as a distinct group of young people diagnosed with and treated for cancer (Bleyer et al., 2017). Adolescent cancer survivorship experiences then were also located within the context of long-term outcomes of childhood cancer. The investigation of adolescents' experiences were not under-taken to better understand the adolescent experience in cancer, but instead was to better understand the medical and psychosocial consequences of being treated for cancer as a child. Prior to a couple of decades ago then, there was almost no research examining the cancer survivorship experiences of adolescents (adolescents being treated for adolescent cancer) separate from their experience of being long-term survivors of childhood cancer.

One of the most dominant and enduring conceptual frameworks of childhood cancer survivorship that continues to be dominant today is that of posttraumatic stress: posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS). This theoretical context was a driving force in early psychosocial oncology survivorship research with adolescents. The earliest conceptualization of posttraumatic stress within the context of childhood cancer was offered by Nir (1985). Based on his clinical experience, he proposed PTSD as a significant theoretical framework for children who have treated for cancer. He noted symptoms that he was treating in his practice with children and adolescents treated for cancer were congruous with posttraumatic

stress disorder. Although his ideas were based on clinical experience and not on standardized or psychiatric assessment, he was the first to propose a stress response from being treated for childhood cancer. A few years later, the psychological effect of bone marrow transplantation in children was acknowledged and studied (Pot-Mees, 1989). Stuber et al. (1991) conducted a series of studies investigating the role of PTSD in survivors of childhood cancer. They presented preliminary longitudinal findings from data collected from young children undergoing bone marrow transplants and concluded that symptoms of posttraumatic stress are experienced up to 12 months following the ending of treatment. This research set the stage for the widespread adoption of posttraumatic stress as the dominant model in understanding the experiences of adolescents who survived childhood cancer. Further, it concretized the perception that cancer was necessarily traumatic. Stuber et al. (1998) argued for the applicability and relevance of a trauma model in use with children and adolescents treated for childhood cancer to inform understanding of long-term psychological sequelae.

Many studies have historically used trauma as a model for the investigation of cancer survivorship experiences of this population. In a small sample of adolescents who had been treated for childhood cancer, Pelcovitz et al. (1998) found that in comparison to adolescents who had been physically abused and healthy adolescents without a history of abuse, adolescents with cancer had a greater prevalence of PTSD. These researchers found that 17% of adolescent cancer survivors met PTSD criteria compared to 11% of adolescent participants who had been physically abused. They also found that adolescents with a history of cancer met criteria for lifetime PTSD compared to only 7% of the adolescents in their sample with a history of abuse. This was a very small sample however as only 73 adolescents participated (23 adolescents with cancer, 27 adolescents who had experienced physical abuse, and 23 adolescents without histories

of cancer or abuse). Similar findings were also found in a study of young adults treated for childhood cancer (Hobbie et al., 2000). Within their sample of young adults, 21% met the diagnostic criteria for PTSD experienced at some point since the ending of treatment. PTSD was also positively correlated with anxiety and psychological distress. In 2001, Kazak et al. validated a new instrument designed to assess cancer-related posttraumatic stress in childhood cancer survivors. This instrument was intended to identify specific factors of the traumatic experience and reaction for survivors that could be assessed and then intervened in.

These results differed from a study conducted by Kazak et al. (1997) who found that adolescent survivors did not experience higher rates of PTSD as compared to controls. Only 5% of adolescent survivors met the criteria for PTSD in this study. This rate of PTSD was supported by studies conducted by Butler et al. (1996) who found that 7% of adolescent survivors met the criteria for PTSD and research by Erickson & Steiner (2001) who reported that 10% of adolescent survivors of childhood cancer met PTSD criteria. A study conducted by Kazak et al. (2004) investigated the prevalence of PTSD and PTSS in adolescents treated for childhood cancer and in their parents. In this study, parents reported more PTSD and PTSS than their adolescent children. Although nearly 20% of families had at least one family member experiencing current PTSD, this was often not the adolescent cancer patient. In contrast to much higher rates found in their parents, only 4.7% of adolescents experienced current PTSD and 8% experienced PTSD at some point since their diagnosis. Of much higher prevalence was posttraumatic stress symptoms which occurred in 17% of adolescents. This echoed an earlier study conducted by Barakat et al. (1997) investigating PTSS within families of children and adolescents treated for childhood cancer. These researchers found that rates of PTSS did not differ between children and adolescents with a history of cancer and children and adolescents

without a history of cancer. However, rates of PTSS were much higher in parents of children and adolescents treated for cancer as compared to parents without a child treated for cancer.

### **Inclusion of PTSD into the DSM-IV**

This body of literature suggests that research on the PTSD and PTSS experiences of adolescent survivors of childhood cancer is characterized by disparate findings. Bruce (2006) argues that PTSD and PTSS are poorly conceptualized and applied within extant research in childhood cancer survivorship. Similar concerns are echoed by Phipps et al. (2014) who examined the prevalence of PTSD and PTSS within a group of children and adolescents who were either in treatment or recently completed treatment for cancer. Within their sample, they found a prevalence of 0.4% of PTSD in the sample and this was comparable to the prevalence in children and adolescents without a history of cancer. Interestingly, the majority of the events found to be traumatic for the adolescents with cancer were un-related to their cancer diagnosis and treatment. They also found no differences between adolescents treated for cancer and adolescents not treated for cancer regarding PTSS. They argue that an assumption of trauma and methodological weaknesses in prior studies have overestimated the prevalence of cancer as a clinically traumatic event. A similar conclusion was articulated in research conducted by Fritz and Williams (1988) who stated that the adolescents they studied in their research were more psychologically healthy than they had assumed.

Shortly following, this discussed proliferation of PTSD-informed research, the DSM-IV included “life threatening illness” as a criterion context for the diagnosis of PTSD (Bell, 1994). Kazak et al. (2004) argue that Stuber et al.’s (1998) preliminary longitudinal work discussed above established the groundwork for this inclusion. Within the DSM-IV, a life-threatening disease was formally recognized as a traumatic stressor for the development of posttraumatic

stress disorder. In earlier versions of the DSM, life-threatening disease was specifically excluded as a criterion context for PTSD (Kangas et al., 2002). Currently, a diagnosis of PTSD can be made following "...an individual experiencing, witnessing, or being confronted with a traumatic death that involved actual or threatened death or serious injury; or a threat to the physical integrity of him or herself or others" (p. 427). Symptoms of posttraumatic stress include: frequent re-experiencing of the traumatic event (often in the form of nightmares and intrusive thoughts), avoidance of thoughts and feelings and emotional numbing, and persistent hyper-arousal (hyper-vigilance and insomnia) (APA, 1994). This inclusion of "life-threatening disease" in the DSM-IV has supported attention and interest both in PTSD research and in clinical interventions (Bruce, 2006; Jacobsen & Jim, 2008; Kangas et al., 2002) as childhood cancer then became formalized as primarily a traumatic event.

This early research into the experiences of adolescents who had been treated for childhood cancer presented very little information on the experiences of being an adolescent diagnosed with and treated for cancer as an adolescent. Not only was the adolescent experience not explored within this body of work, this cross-sectional research offered a pervasive trauma discourse. To some children and adolescents, cancer is a traumatic event and the use of PTSD and PTSS are important theoretical frameworks to implement. However, this reliance on trauma frameworks have narrowed inquiry into adolescents' experiences. Historically, little was known outside this trauma discourse and it offered a unitary perspective of the psychosocial experiences of being treated for cancer as a child or adolescent. Moving in from cancer survivorship, the next sections of this chapter will provide an overview of how posttreatment has been conceptualized and understood for adolescents treated for cancer as adolescents.

### **Posttreatment Experiences of Adolescents**

Much of what is known about the after-cancer experiences of adolescents is influenced by the above legacy of cancer survivorship. However, over the past decade, greater attention has been directed towards a more immediate posttreatment period of time. It within this body of work, that posttreatment has begun to be understood as a distinct period of time within the unbounded trajectory of cancer survivorship. In what follows, I discuss research that has explored adolescents' experiences within a posttreatment period of time. In line with the aims of this study, I have not included literature that does not involve adolescents or studies that are beyond a posttreatment period of time.

There have been a few studies that have investigated the psychosocial impact experienced during posttreatment. For example, Zebrack et al. (2014) found that AYAs ages 15-29 who were 4-22 months following the end of treatment identified both positive and negative aspects of having experienced cancer. These aspects included: fears related to cancer and recurrence, managing distress and other emotions, struggles to maintain normalcy, lost peers and also renewed purpose in life and opportunity for personal growth. Positive and negative aspects of cancer were also identified in a study by Bellizzi et al. (2012) which looked at differences in psychosocial impact between adolescents and young adults. Both age groups experienced negative impact on financial wellbeing, body image, control over life, work plans and social relationships. Both groups also experienced positive impact regarding plans for the future and health competence. Adolescents specifically experienced both a more negative impact on relationships with peers and concerns about education and also a more positive impact on relationships with parents when compared to young adults treated for cancer.

Most of the research involving adolescents' experiences during posttreatment has been framed by psychological distress. Like the unitary conceptualization of cancer survivorship proposed above, I suggest here that posttreatment has evolved predominantly within a distress framework. AYAs diagnosed with cancer are believed to be a particularly vulnerable group of patients to experience distress due to the psychosocial and medical impacts I have discussed in an earlier section combined with the simultaneous demands of cancer with the stresses experienced with physical and psychosocial development (Rae et al., 2019). Posttreatment as conceptual understanding has evolved predominantly within a psychological distress framework and psychosocial oncology research is increasingly producing statistical data on the posttreatment experiences of AYAs treated for cancer. How young people experience posttreatment, and the meaning they may hold of these experiences, has been largely overlooked and was therefore a critical underpinning of my dissertation research.

### **Psychosocial Distress**

Psychosocial distress is common among cancer patients of all ages and stages of their disease and has a significant impact on a patient's quality of life throughout cancer treatment and following the completion of treatment (Bultz et al., 2011; Mehnert et al., 2017; Xie et al., 2019). Distress is described by the National Cancer Institute as a complex, unpleasant emotional experience characterized by compromised psychological and/or spiritual well-being that can vary in severity and duration (NCCN, 2009). Practically, both in research and clinical practice, distress is often understood as both clinical and sub-clinical levels of depression and anxiety (Howell & Olsen, 2011). Screening for distress has been suggested as a vital assessment of patient-wellbeing within oncology patient care and has been proposed as the assessment of a 6<sup>th</sup> vital sign of cancer care (Bultz et al., 2011). Standardized screening has become implemented in

many adult oncology settings although some have argued for refining the validity and utility of distress screening in cancer care (Salmon et al., 2015). This distress movement across (predominantly adult) cancer centres across North America has resulted in heightened clinical and research attention to identifying and responding to psychosocial distress in cancer patients (Smith et al., 2018; Zebrack et al., 2015). In Canada, the *CDS-AYA: Cancer Distress Scales for Adolescents and Young Adults* was developed for use with adolescents and young adults diagnosed with cancer. There is considerable validity evidence of this tool developed to assess AYA patient wellbeing (Rae et al., 2019; Tsangaris et al., 2019).

Although distress is a significant and meaningful indicator of patients' wellbeing within the cancer experience and along the cancer trajectory, the outcome of this increased attention on distress in cancer patients, has positioned posttreatment research as focusing almost exclusively on the prevalence of distress in AYAs diagnosed with and treated for cancer. Increased awareness of the distress in cancer patients, the recognized psychosocial impact of a diagnosis of cancer for adolescents and young adults, and the historical legacy of PTSD/PTSS, have all likely fueled this dominance of distress investigation and exploration during a posttreatment period of time.

### **Distress and Adolescents**

Adolescents and young adults have been found to experience high levels of distress following a diagnosis of cancer (Dyson et al., 2012). Although increased distress has been found in adolescents on-treatment compared to being off-treatment (Miroshnychenko et al., 2021), the presence of psychological distress has been extensively studied in adolescents and young adults following the completion of treatment.

One of the earliest posttreatment studies involving adolescents was conducted by Kwak et al. (2013a) who examined changes in psychological distress experienced by adolescents and young adults (ages 14-39) over the year following a cancer diagnosis. At twelve months following diagnosis (early posttreatment time), 23% of participants experienced clinically significant levels of distress that exceeded population norms. This rate was higher than the prevalence of distress assessed at six months. After twelve months following the end of treatment, the authors report that distress declined over one year which was statistically significant. These findings are similar to those of Zebrack et al. (2014) who also investigated the trajectory of distress over the twelve-month interval following a cancer diagnosis for AYAs ages 15-39. These researchers found that over the course of twelve months, 47% of AYAs experienced distress at some point along the trajectory. Specifically, 12% experienced chronic distress throughout the twelve months, 15% experienced increased distress at twelve months, and 20% experienced improved distress at twelve months. A study by Canning et al. (2014) studied the emotional distress of adolescents ages 12-18 within five years from the completion of treatment. They found that 69% of participants had distress scores at clinically significant levels yet their investigation of psychological, demographic, illness and treatment-related potential risk factors did not provide any variance in distress levels. They did determine that perceptions of self-concept did predict distress. Findings of clinically significant levels of distress of AYAs during posttreatment was also demonstrated in a study by McCarthy et al (2016). 48% of AYAs scored above clinical cut-off scores for PTSS and 31% of participants reported moderate to severely elevated symptoms of anxiety and depression. Female gender, less social support, and challenges with self-image and identity were found to be indicators of higher distress.

Studies have also investigated the prevalence of mental health symptoms of AYAs during posttreatment. Moderate rates of anxiety and depression were found in a study that examined the mental health experiences of adolescents and young adults (ages 15-39) who were either in treatment or had completed treatment within the previous two years (Muffly et al., 2016). Twenty-three percent of AYAs reported anxiety and 28% reported depression. 13% experienced diagnostic posttraumatic stress and 46% had posttraumatic stress symptoms. Unfortunately, this study grouped participants in treatment and off treatment together and did not offer analyses comparing differences between these two groups. More than half of AYAs in this study were also found to have posttraumatic symptoms. Finally, a qualitative study that explored cancer-related distress as experienced by AYAs ages 15-25 who had completed treatment eighteen months to six years prior to their study participation identified distress-related themes accounting for their experiences during posttreatment (Ander et al., 2018). Some of these themes included: having completed treatment but not feeling cancer free, feeling like the “one” with cancer, developmental impact, social isolation, the awareness of the fragility of life, and a time of experiencing significant emotions.

### **Comparisons of Distress**

The above studies support a moderate prevalence of distress for AYAs treated for cancer within a posttreatment period of time. There has also been a small body of research that has sought to understand if adolescents and young adults treated for cancer are at greater risk for developing distress and mental health diagnoses compared to other cohorts. Initial studies suggest that adolescents and young adults experience more prevalent and severe levels of distress compared to both other oncology patient age cohorts and to AYAs not treated for cancer. (Lang et al., 2015; Wang et al., 2014). A recent study by Lane et al. (2021) found that AYAs (ages 15-

39) who had completed treatment experienced significantly greater levels of distress when compared to age-matched peers without a history of cancer. 27.9% of participants reported severe distress. Indicators of higher distress in AYAs treated for cancer included: body image dissatisfaction, poor social support, elevated fears of cancer recurrence, and not attending school or working. The severity of distress was largely independent of demographic and cancer variables which was similar to the conclusions drawn by Canning et al. (2014). A population-based study conducted by Lang et al., (2017) looked at self-reports of mental health and diagnosed mood and anxiety disorders among AYAs with and without a history of cancer. AYA survivors of cancer (ages 15-39) were both more likely to report mood and anxiety disorders and to be diagnosed with mood and anxiety disorders compared to AYAs without a history of cancer and older adults (ages 40+) who were cancer survivors. Notably, 15% of AYAs with a previous cancer diagnosis reported a diagnosis of anxiety compared to 5% of AYA without a cancer history. Similarly, 15% of AYAs who had been treated for cancer reported a diagnosis of depression compared to 6% of AYAs without a history of cancer. A similar finding was also reported in a study conducted with children and adolescents ages 8-18 who were on and off treatment (1-9 years) and compared to healthy age-matched peers (von Essen et al., 2000). Children and adolescents who had completed treatment reported higher rates of anxiety and depression compared to their peer group without a history of cancer. It is important to note though that this study had a very small sample size of only 35 participants. Finally, a recent systematic review and meta-analysis conducted by De et al. (2020) found that in comparison to AYAs without a history of cancer, AYA ages 15-39 treated for cancer, experienced more mental health symptoms and diagnosed mood and anxiety disorders. These authors concluded that

AYAs treated for cancer were at an increased risk for developing mood and anxiety disorders compared to AYAs in the general population.

Different results were found in a study by Larsson et al. (2010). Rates of anxiety and depression were examined for adolescents ages 13-19 diagnosed with cancer at varying intervals from diagnosis and compared to age-matched peers without a history of cancer. At twelve months following a cancer diagnosis, adolescents reported worse mental health in comparison to population norms. However at eighteen months (early posttreatment) following the diagnosis, there was no difference between the two groups. At twenty-four months following diagnosis (approximately twelve months following completion of treatment), the cancer group reported lower levels of anxiety and depression in comparison to healthy peers. The authors of this study suggested that anxiety and depression may decrease over time for adolescents with cancer.

As I suggested earlier, the pervasive use of the construct “AYA” has blurred possible distinctions between the experiences of adolescents and young adults in extant research. Much of psychosocial oncology research has assumed this group of young people (adolescents and young adults) to be a homogenous group and very little is known about the adolescent experience within posttreatment apart from its combination with the young adult experience. This single grouping of adolescents and young adults has created a notable and significant gap in understanding the experiences of adolescents specifically both in research and in practice (Haase & Phillips, 2004). There is significant developmental heterogeneity within and between adolescents and young adults. Emerging adulthood, ages 18-25, has been argued as a distinct developmental period with unique developmental experiences. Emerging adults perceive themselves as having left adolescence but have not yet entered adulthood (Arnett, 2000). This underscores the importance of understanding, and conceptualizing, the adolescent experience

within cancer as potentially distinct and different from that of young adults diagnosed with cancer.

Within most of the studies discussed above, the experiences of adolescents and young adults were not investigated separately. However, in the few studies that have separated these groups of young people, adolescents have experienced better mental health outcomes in posttreatment when compared to young adults. A study conducted by Larsson et al. (2010) found improvements in depression and anxiety at eighteen months following the completion of treatment for adolescents. In this study, adolescents treated for cancer demonstrated more improved mental health as compared to young adults. Another study conducted with AYAs still in treatment, found a significant difference between the distress, depression, and anxiety experienced by adolescents and young adults (Xie et al., 2017). Overall, 89% participants experienced distress and 90% experienced symptoms of depression and 75% experienced symptoms for anxiety. Interestingly, adolescents ages 15-20 and adults ages 36-40 reported the lowest scores and young adults ages 21-25 reported the highest scores for distress, depression and anxiety. De et al. (2008) in their systematic review and meta-analysis also found that in their study of AYAs' mental health outcomes during posttreatment, an older age at diagnosis (being a young adult) was associated with increased mood and anxiety disorders.

These few studies suggest that the distress experiences of adolescents and young adults is possibly unique: adolescents have not experienced the same prevalence of distress and impact to mental health as young adults have during posttreatment. It is not possible to draw a conclusion from a few studies but they hint at the unique posttreatment experiences for adolescents and young adults. The dominant prevalence of distress identified in AYAs may not reflect the experiences of adolescents during posttreatment and does not recognize perhaps the different

reasons for distress experienced by adolescents and young adults. The inclusion of adolescents and young adults within the same cohort has universalized the assumptions of distress for both adolescents and young adults and it remains relatively unknown what the specific experiences of adolescents during a posttreatment period of time might involve.

### **Adolescents and Mental Health**

Extant research has drawn attention to both the development of distress and the development of mental health symptoms and disorders occurring for AYAs following the completion of cancer treatment. This body of research has most often been cross-sectional in design: it is unknown what their distress and mental health symptoms were like prior to their cancer diagnosis. Research investigating the mental health outcomes of adolescents following the completion of cancer, have held assumptions that a cancer diagnosis creates mood disorders and anxiety for adolescents and young adults (AYAs). Prevalence of these have been highlighted in studies as psychosocial impact from a cancer diagnosis and treatment. Adolescence is a time for the onset of development of many mental health disorders (Bor et al., 2014). Kessler et al. (2009) discuss that the World Health Organization estimates that many mental health disorders commonly occur in childhood or adolescence. Mental health disorders are found to have much earlier ages of onset than most chronic physical disorders and are associated with the onset of physical disorders and adverse life course outcomes.

Although increased rates of mental health distress and trauma symptomatology are widely accepted as an outcome of a cancer diagnosis in adolescents and young adults, these rates closely match those seen in AYAs without a history of cancer. Rates of depression and anxiety from the studies above reviewed range from: 15-28% for depression and 15-23% anxiety for

AYAs treated for cancer. A notable difference was the study by Xie et al. (2017) who found that depression for AYAs was 90% prevalence for depression and 75% for anxiety.

The rates of mental health discussed in the articles I have reviewed in this chapter aligns with the prevalence of these diagnoses in adolescents without a history of cancer. This section will briefly address and contextualize depression, anxiety, and trauma symptoms in adolescents generally.

### ***Depression***

Thapar et al. (2012) discuss that adolescent depression is often not recognized as it is attributed to the normal emotional affect of adolescents and therefore likely an under-diagnosed medical condition. Depression is rare in childhood but begins to rise in early adolescence and rises more sharply in girls than in boys (Maughan et al., 2013). Depression rates rise throughout adolescence with some estimates of depression up to 20% in late adolescence (Graber, 2004; Hankin et al., 1998; Lewinsohn et al., 1999). In early adulthood, the prevalence of major depressive disorders range from 10%-17% (Moffitt et al., 2010). A family history of depression, exposure to stressful life events, and psychosocial stressors, have all been identified as significant risk factors for the development of depression (Thapar et al., 2012). Identified psychosocial risks include: family bereavement, separations and conflict, child abuse and neglect, and peer conflict and bullying (Jaffee et al., 2002; Kendler et al., 2000). Depression in adolescents has been associated with multiple adverse outcomes that extend into adulthood and often reoccurs throughout adolescence (Dunn and Goodyer, 2006).

### ***Anxiety***

Rates of anxiety range from 6%-18% for adolescents (Graber, 2004). Anxiety disorders are a significant mental health concern for adolescents and the most prevalent mental health

diagnosis (Siegel & Dickstein, 2012). Merikangas & Burstein (2010) estimate that the prevalence of anxiety in adolescents is 31%. Unfortunately, anxiety is also significantly under-treated with only 18% of adolescents receiving treatment for this diagnosis. Although there are a variety of anxiety disorders experienced by adolescents, they share similar features (Siegel & Dickstein, 2012) and therefore are collapsed together in a prevalence rates. Similar to depression, anxiety often begins at puberty or shortly before. A median age of 11 was determined as the onset of anxiety from by an American national study (Kessler et al., 2007). This mental health disorder is also seen in more adolescent girls than boys and creates widespread impact in functioning within different realms (Siegel & Dickstein, 2012).

Prevalence of these diagnoses are lower in adolescents and young adults locally. In BC, the Adolescent Health Survey (2018) involving adolescents throughout the province reported that 15% of adolescents had experienced depression and 19% of adolescents experienced anxiety. This rate increased 5% and 11% respectively in adolescents from the previous survey conducted in 2013.

It is difficult to determine the distress and mental health experiences of adolescents treated or cancer when they have been investigated along with those of young adults. It is not clear from extant research what impact a cancer diagnosis and treatment might have in these domains. Taken together, this body of work on the distress and mental experiences demonstrates that some adolescents experience distress and negative mental health impact. However, in addition to the considerations I have noted above, the interpretation of these studies must also be contextualized by the research designs utilized. These studies ranged widely in design, sample size, and instruments used for distress measurement and assessment of mental health. The focus of posttreatment has remained narrow within this research. However, I will now briefly discuss

two conceptual frameworks that have begun to become increasingly applied to inquiry into the posttreatment experiences of adolescents and young adults.

### **Unmet Needs**

With the awareness of the prevalence of distress, and the need to identify and respond to AYAs experiencing distress, there has been a small body of research that has evolved to better understand the unmet needs of adolescents and young adults who have completed treatment for cancer. A systematic review conducted by Galan et al. (2016a) found that adolescents and young adults experienced some common needs following the end of treatment: individualized information and advice, counselling and psychological support, and social support and social relationships. Bibby et al. (2017) also identified AYAs' expressed need for peer interaction that was unmet following the end of treatment. Galan et al. (2016b) found that adolescents and young adults had a variety of needs after treatment ended and all were identified as significant to AYA patients during posttreatment.

The most commonly identified need by AYAs during posttreatment was for counselling and psychological support. Due to the complexity of psychosocial experiences that AYAs are faced with throughout the cancer trajectory, a particular need for psychosocial support has been identified for AYAs (Harlan et al., 2011; Zebrack et al., 2012). Unfortunately, a number of studies have demonstrated that adolescents and young adults perceive many of their needs to be unmet as cancer patients including psychosocial support (Bibby et al., 2017; Harlan et al., 2011; Keegan et al., 2012; Kent et al., 2013; Millar et al., 2010; Smith et al., 2013; Tsangaris et al., 2014). A study of AYAs ages 15-25 within a posttreatment period of time identified barriers experienced following the completion of treatment (Holland et al., 2021). The most significant barriers existed in accessing psychosocial support which was identified as necessary following

the end of treatment. Two or more healthcare support needs were also identified by 60% of AYAs (ages 15-25) following treatment completion (Sawyer et al., 2017). This rate was similar to unmet needs experienced by AYAs during treatment. Interestingly, AYAs who had two or more unmet needs experienced greater emotional distress during posttreatment. The specific needs that were correlated with distress were: access to a social worker for emotional support, pain management, and access to education and vocational support. A study conducted by Zebrack et al. (2014) also found that unmet counselling needs reported by AYAs at twelve months following their cancer diagnosis, was also significantly associated with distress.

The heightened attention to distress experienced by adolescents and young adults during posttreatment has created the need to better understand their experiences pragmatically following the end of treatment. This attention to unmet needs likely reflects gaps in understanding the diversity of the cancer experiences of adolescents and young adults.

### **Quality of Life**

Health-related quality of life of adolescents and young adults during following the completion of cancer treatment has also been investigated in recent work. Felder-Puig et al. (1998) acknowledge the complexity in definition of this term but it can be understood as a broad and comprehensive concept that includes subjective evaluations of the different domains of one's life. Within a cancer context, it refers to symptom burden from disease and physical and psychosocial functioning within one's life. A systematic review was conducted with studies involving AYA survivors (ages 15-39) that included any psychosocial variables impacting quality of life (Quinn et al., 2015). Although very broad inclusion criteria, the authors conclude that AYA survivors were more likely to have worse or impaired quality of life as compared to the general population. However, the analysis criteria are not clear from this study and very few

of these studies included post-treatment experiences of adolescents. A similar finding was also shared in a study conducted by Smith et al. (2013). These authors investigated ratings of physical and mental health quality of life across age groups and with healthy peers ages 15-39. They found that AYA patients had significantly worse health-related quality of life as compared to healthy population norms across both physical and mental health domains. Further, they found that adolescents (ages 15-17) reported worse physical quality of life and worse school/work functioning. A recent study investigated differences between adolescents, emerging adults, and younger adults and the wider population on a variety of different psychosocial and medical domains representing quality of life (Siembeda et al, 2020). Clinically relevant differences between this sample and the wider population were found only for anxiety and depression. Interestingly and supporting the point I offered earlier, adolescents reported significantly fewer symptoms and better psychosocial and medical functioning as compared to both emerging adults and younger adults.

### **Conclusion**

This chapter traces the development of how adolescents have come to be understood within the context of a posttreatment period of time. Within this chapter, I have offered an overview of the contextual layers that have informed their posttreatment experiences. I began with an overview of what has informed the understanding of adolescents as a unique population. I considered pathophysiological, psychosocial, and systemic factors that have contributed to this understanding. I then offered a historical overview of cancer survivorship and located adolescents in this history. I then narrowed the focus of after-treatment experiences and discussed extant literature on posttreatment experiences for adolescents. I offered a context of adolescents' mental health to supplement how the distress and mental health experiences are

considered for adolescents. Finally, I briefly offer two other conceptual frameworks- unmet needs and quality of life- that have emerged as alternate, but still related, ways to understand AYAs' posttreatment experiences.

Many of the studies discussed demonstrated the adverse impact that cancer can have on the wellbeing and lives of many adolescents and young adult. These studies have advanced attention to a posttreatment period of time and have also raised the awareness of the experiences of adolescents and young adults following a cancer diagnosis. I have also outlined though the gap that this distress research has for understanding specifically adolescents' experiences with distress in posttreatment and my belief that adolescents experience posttreatment differently than young adults. The thread I have carried throughout this chapter is that the posttreatment experiences of adolescents have been defined and conceptualized narrowly in extant research. The body of posttreatment research has been limited by a focus on psychological symptoms and although distress and mental health symptoms have been demonstrated to be meaningful indicators of posttreatment experiences, their dominant focus has obscured attention to other experiences within a posttreatment period of time. Implicit in my dissertation research is an argument and call for a wider scope of research inquiry regarding adolescents' experiences during posttreatment.

I have suggested that the history of cancer survivorship has informed the extensive application of distress as a dominant paradigm within which to understand adolescents' experiences. The historical perception and construction of adolescents within cancer survivorship research has had significant consequences regarding advancing research involving adolescents. Firstly, relatively little is known of posttreatment experiences outside of trauma, distress, or mental health. Secondly, little is also known about the adolescent experience during

posttreatment. Until recently, almost no research explored the experiences of adolescents within the context of cancer. The experiences of adolescents diagnosed with and treated for cancer as adolescents has been very mildly explored as much of the research on involving this group of people has historically been with adolescents treated for cancer as children or adolescents have been included with young adults as a homogenous cohort. From the very few studies that have examined the lives of adolescents who have completed treatment for cancer, these studies suggest that the adolescent experience is unique and under-explored. Finally, there has been little diversity in methodology and research design within the exploration of posttreatment experiences. There has been little qualitative inquiry and little research with a focus on exploration rather than investigation. Distress is a complex and multi-factorial experience. Within most of these quantitative studies, generalized measures of distress have been utilized and specific aspects of distress have not been studied. These generalized measures do not account for the complexity of distress and an absence of correlates for investigation, provide little information for who might be at risk for developing distress.

Philosophical hermeneutics suggests that the language that is used to describe or refer to something substantiates it: language interprets for us in a certain way how we relate to a topic and how a topic comes to be known (Gadamer 1960/2004). Posttreatment has a historically-shaped cultural vocabulary and this language has perpetuated a dominant construction of understanding this period of time. The background and review of literature that I have offered within this chapter have established the cultural horizon of posttreatment experiences as I have come to understand them for adolescents. Although there has been a burgeoning of research on posttreatment, there remains gaps within this inquiry. Implicit within this body of research are questions of posttreatment experiences that remain. There is a dearth of understanding of how

adolescents experience posttreatment and the meaning of living within a posttreatment period of time. By interpreting the voices of adolescents involved in my dissertation study, I believe this work moves beyond distress as constitutive of posttreatment and considers other significant aspects of their posttreatment experiences.

## **Chapter Three: Conceptual Overview of Adolescence**

### **Introduction**

The previous chapter presented a topical overview of the posttreatment experiences of adolescents who have been diagnosed with cancer. It was important to begin this review there in order to situate the topic of my dissertation research within how it's been traditionally known. As I argued, the historical construction of this topic has wielded tremendous influence over how the experiences of adolescents at this time in the cancer trajectory have been understood and responded to. This construction has also supported a privileging of how this posttreatment period of time has been studied and understood, rather than on an examination of how adolescents have come to be known within this examination. In this chapter, I move from a topical overview to a review of broader epistemological concepts that inform how adolescents are understood socially and within research inquiry.

In the previous chapter, I explored how extant research has conceptualized the posttreatment experiences of adolescents with cancer. I discussed that the dominant focus of research inquiry on psychological distress, the current state of the under-representation of AYAs in oncology research in general, and the prolific usage of "AYA" that combined the experiences of adolescents along with young adults, has created a context where the understanding of adolescents' experiences following the completion of cancer treatment is both under-explored and under-developed. This review was a necessary foundation on which to situate my research study as it provides an overview of what informs understanding of adolescents' posttreatment experiences. I argued throughout this review that despite a growing body of literature, there remains little known about the experiences of this group of young people.

This secondary component of my review offers a review of epistemological ideas and concepts that inform how we think about adolescents more generally. Although these conceptual frames are often not explicitly articulated in health research, their accompanying assumptions and premises, inform how adolescents are understood as these assumptions are situated within theoretical considerations. This review is thus an important component of my dissertation research. I offer that it supports my analyses to move beyond traditional psychosocial assumptions and expectations of both adolescents and posttreatment experiences. To meet this challenge and to position my analysis, I turned to ideas and concepts that would help both deepen both my analysis and understanding of both adolescents and posttreatment and also deepen the history of the topic of my dissertation research.

Finally, this chapter considers adolescence as a tradition of meaning. Within such a tradition, cultural and social discourses are informed by the influence of this tradition (Gadamer, 1960/2004). This focus aligns well with philosophical hermeneutics and the idea of historicity. The ability to see adolescence contemporarily requires the consideration of how this topic has been situated both historically and ontologically. The understanding of adolescence has not been static and this chapter is an effort to see adolescence in its background of related assumptions, ideas and meanings: its horizon (Gadamer, 1960/2004).

### **Considering “Adolescence”**

Increasingly, adolescents are being offered distinct consideration and attention within health care practice, policy, and research (Lerner & Steinberg, 2009). I argued in the previous chapter that the usage of “AYA” in oncology has both widened the collective experiential lens on adolescents and young adults but that this prolific usage has also narrowed this gaze on the

experiences of adolescents as a distinct group of oncology patients. Within a focused gaze on adolescents, there should also be an examination of the meaning of “adolescence.”

Interpreting the meaning of adolescence is often not articulated but has significant influence on how adolescents have been studied. In psychosocial oncology research specifically, the dominant interpretation of adolescence has both paradoxically homogenized the experiences of adolescents at the same time as differentiating the construction of AYA patient experiences from those of other individuals diagnosed with cancer. Further, the prolific use of “AYA” has commanded a unitary definition and understanding of adolescents and young adults diagnosed with cancer. This has created assumptions about this population and how their experiences might be impacted by a cancer diagnosis.

### **The Ontological Underpinnings of Adolescence**

“Adolescence” is an interpreted concept: it is not an objective entity. Further, it can be understood as an essentially contested concept. Gallie (1955) defined essentially contested concepts as ones where the presence of the concept is generally acknowledged but there is disagreement regarding the constitution and meaning of the concept. This categorization lends itself well to “adolescence” as this is a concept with an accepted existence yet holds various interpretations regarding what “adolescence” means. Although adolescence is often perceived as a fixed developmental period, the definition and understanding of adolescence is situated both ontologically and historically which has informed its varying interpretations (Côté, 2014).

Youth scholar James Côté (2014) argues that within the field of youth studies, a significant fissure exists between those who subscribe to a realist vs a nominalist ontological position regarding the nature of adolescence. The central question wrestled with by both sides is: does “adolescence” exist? Realists argue that adolescence has a reality independent from how it

is defined and conceptualized: it exists as a naturally occurring human experience. Conversely, Côté discusses that nominalists argue that adolescence is socio-culturally constructed: the understanding of adolescence is contextually rooted in time and space. Acknowledging the location of “adolescence” within an ontological context is not explicitly articulated within adolescent psychosocial oncology research and yet has significant implications for how adolescents are studied.

### **Philosophical Realism**

The context of oncology research is typically biomedical in orientation: it is rooted in the body. The body as a source of understanding has influenced not just medical research in oncology but also psychosocial inquiry. In this view, adolescents are understood in reference to their body. With regards to the ontological distinction noted above, psychosocial oncology research typically upholds a philosophical realist approach to understanding adolescents. Within this perspective, the time of adolescence begins with puberty and is assumed to be a universal and natural phase of human development.

### **Defining Adolescence**

The historical defining of the term adolescence supports a philosophical realist perspective. Within industrialized society, adolescence is considered as the period of time stretching from childhood to adulthood (Lerner & Steinberg, 2009). Historically, the period of adolescence was defined by the World Health Organization to comprise ages 12-17. However, it has been suggested that this chronological threshold is no longer accurate (Sawyer et al., 2018). The World Health Organization now defines the period of adolescence to be from 10-19 years of age (World Health Organization, 2021). With improved health and nutrition, earlier puberty has accelerated the earlier onset of adolescence throughout the developed world. The WHO also

formally acknowledges that chronological age is only one dimension of defining adolescence and that age does not capture the social transitions that are part of this period of development.

Not only has the definition of the beginning of adolescence shifted, the end of adolescence is also difficult to demarcate in the industrialized world. The transition to adulthood has become increasingly delayed due to economic changes impacting their life-course (Arnett, 2004). The end of adolescence, and the onset of adulthood, are also defined by the legal cut-offs that surround the understandings of these periods of time. Age is perceived as a legal cut-off and determinant for life events such as education, employment, marriage, and parenthood. In some regions of the world, adolescents are living longer with their parents, attending post-secondary education, and postponing marriage and children due to shifts in economic conditions during the twentieth and twenty-first century (Furstenberg et al, 2005). The WHO definition of adolescence noted above extends the historical upper age of adolescence to age 19. This definition fits with how the age range of adolescence is understood in Western popular culture (Sawyer, et al., 2018). Extending the upper age of adolescence beyond 19 has also been suggested. Sawyer et al. (2018) argue that the end of adolescence should be extended to 24 years: the age of adolescence constituting ages 10-24.

Arnett (2004) discusses five developmental markers that are significant transitions to adulthood and that have been delayed for young people in contemporary Western society. These transitions include: leaving home, completing education, beginning a career, marriage, and parenthood. In Western society, these social and roles transitions are occurring later for young people than they had been previously. Arnett (2000; 2007) argues that instead of conceptualizing the end of adolescence as extending past age 19, that instead, older adolescents and young adults, constitute a new category of human development. He uses the term “emerging adulthood” to

refer to those ages 18-25. Emerging adulthood is proposed to be theoretically and empirically distinct from both adolescence and adulthood and Arnett argues that the experiences of young people during this period of time are not just due to extended transitions into adult roles but instead, constitute a new life course period (Arnett 2000; 2007).

However, Arnett's proposition returns to an age-bound stage approach to understanding adolescence. Although he directs attention towards the increasingly prolonged transition to adulthood due to shifting social and economic realities experienced by young people, he also considers adolescence, emerging adulthood, and adulthood as discrete categories. Within this approach, development is considered as a pre-determined series of stages young adults move through. These periods of development though have been recognized as blurring together due to evolving social and economic changes faced by this group of young people (Hendry & Kloep, 2007). The framework of emerging adulthood also suggests that the onset of adulthood starts at a certain time. However, development is non-linear (Baltes, 1997) and development is domain specific: young people will develop different developmental domains at different times (Hendry & Kloep, 2007). Finally, within a stage-based approach, there is an assumption of universality: all young people will progress through these stages. Some have argued that the claim of emerging adulthood does not account for diverse social and cultural contexts and demands (Bynner, 2005). Emerging adulthood then is an experience grounded in certain societies with a certain aged group of young people experiencing particular social realities. Development is not caused by chronological age but rather the context within which young people are embedded. Hendry and Kloep (2007) argue that the concept of emerging adulthood does not add to contemporary understanding of human development.

However the ending of adolescence is conceptualized, these perspectives support the understanding that adolescence is socially constructed and includes both biological and social ‘facts’ which evolve and change. The changing parameters and shifting dimensions involved in the definition of adolescence hint at the adoption of considering a nominalist philosophical lens. However, the dominant use of a realist perspective has created implications for the study of the adolescent experience in oncology. Firstly, it has meant that there is little variability regarding how adolescents have been studied in terms of impact to their development. There is very little inquiry in psychosocial oncology that does not examine the impact of a cancer diagnosis on the achievement of developmental milestones. Secondly, with the assumption of a universal experience shared by adolescents, the time of adolescence is believed to be a common and similar experience with little diversity or difference: the perception of the adolescent experience in oncology has become homogenized and based on evidence from certain (industrialized) countries. Although this traditional ontological stance has offered significant contributions regarding aspects of the cancer experience that impact adolescents, this stance has focused inquiry in a specific direction. This focus may ignore aspects of adolescents’ experiences that fall outside of developmental norms and also may fail to appreciate the breadth of adolescents’ socially and culturally informed experiences.

### **Developmental Milestones**

The extensive use and reliance on developmental milestones to conceptualize the psychosocial experiences of adolescents with cancer is another enactment of philosophical realism. Within oncology, psychosocial development is traditionally understood by the achievement of developmental milestones. There are a variety of recent studies that have demonstrated the significant impact of cancer on adolescents’ psychosocial development which I

have discussed in the previous chapter. Such key studies have begun to delineate the distinction of the AYA cancer experience as compared to other age groups. Developmental milestones can be a helpful means to frame and understand the psychological impact of a cancer diagnosis on adolescents, however, this focus has limited inquiry beyond the outcomes on various developmental norms of adolescence.

Developmental milestones are markers of physical and psychosocial development and are significant markers of the transition to adulthood (Havighurst, 1948). Developmental milestones have not only been perceived as a process of transition to adulthood but the achievement of them is believed to be significant to the development of adult quality of life and emotional adjustment (Maurice-Stam et al., 2007). Psychosocial oncology has made extensive use of developmental psychosocial milestones as markers of adolescent development following a diagnosis of cancer. There are references to developmental milestones throughout psychosocial oncology research and adolescent psychosocial development is perceived as the successful acquisition of these age-appropriate milestones (Abrams et al., 2007).

The extensive references to the acquisition of developmental milestones in psychosocial oncology research supports certain developmental norms assumed in oncology. This creates the image of normative development in this context. Although this isn't acknowledged explicitly in this body of research, implicitly these norms appear to be those supported by the work of educational researcher, Robert Havighurst, who (1948) created an influential theory of psychosocial development. He suggested that human development can be conceptualized as a series of developmental tasks that are completed at distinct times in a person's development. He proposed that successful achievement of these tasks is necessary for adaptive social functioning and quality of life. Although he developed this idea of developmental tasks in the context of

educational theory, this approach to understanding adolescent psychosocial development has become quite dominant. Havighurst (1948) identified developmental tasks which he believed were necessary tasks to be completed in adolescence. These tasks include adjustment to rapid physical development, accommodation to enhanced cognitive abilities at school, maturing verbal competence, development of personal identity, vocational planning, a sense of autonomy and independence, development of peer relationships, managing sexuality and sexual development, adopting a personal value system, and manage and control risk-taking.

Identifying psychosocial concerns introduced by a cancer diagnosis is instrumental in the care of adolescents diagnosed with cancer. Although the framework of developmental tasks is an accessible approach to understanding the psychosocial development of adolescents, these normative assumptions of markers of successful psychosocial development are strongly embedded in both AYA oncology clinical care and research. This supports a unitary perspective in understanding the psychosocial development of adolescents.

### **Task vs Stage Approach**

Côté (2014) differentiates two different paradigms to conceptualize the development of adolescents. One is a stage-based developmental approach. He argues that Hall's legacy of "storm and stress" has supported the propagation of social and scientific belief that adolescence is a specific developmental life stage and an identified stage of development within the trajectory to adulthood. Although some developmental theories have suggested more nuanced perspectives, this approach is still pervasive and has influenced how adolescents are understood. The second approach to considering the life-course of adolescents is informed by social constructionism and he refers to this as age-status. This perspective suggests that adolescence is a status believed to be defined by age and carries normative assumptions about this developmental time supported by

socio-cultural expectations. This is supported by the work of Snarey and colleagues (Snarey et al., 1983) who argue that adolescence should be considered as a cultural age.

The legacy of a stage-based approach to understanding human development has been pervasive within the study of adolescents in psychosocial oncology. Not only has it constrained how the adolescent oncology experience is understood and studied, but it has also essentialized adolescence by upholding the notion of universality of “adolescence”: that adolescents are the same regardless of socio-cultural context. Hammond (2017) argues that a task-based stage model should not be used to conceptualize AYAs. He challenges both the construction and perception of the homogeneity of AYAs with cancer and also the universal assumptions of adolescence inherent within these constructions. He suggests that this task-based discourse blurs the intersectionality of identities and subsequent distinctness within AYAs with cancer that is not represented within extant psychosocial oncology research.

### **Nominalism**

A nominalist perspective to defining adolescence supports a socially constructed view of this developmental time. Within this paradigm, social realities are created and maintained by history, social relations, and institutions. These ways of understanding the world are absorbed back into this construction and become constitutive of what is being examined (Gergen, 2015). Foucault (1975) advises cautions toward the power of socially constructed concepts with the term “regimes of truth” to refer to the dominance that certain social perceptions hold. He suggests that these operate much like self-fulfilling prophecies that are mutually reinforced when ways of thinking about concepts, such as adolescence, intersect with institutionalized practices to produce a society that thinks and feels about adolescence in a unitary manner. As will be

discussed in a forthcoming section, dominant ways of perceiving adolescence have become constitutive of how they are understood in psychosocial oncology.

Psychologist William Kessen (1979) challenges the historical positivist definition of “the child”. He proposes that there were numerous developments within twentieth-century that led to the cultural “invention” of the modern-day child in the United States. He effectively argues that although “the child” can appear as a positivist entity, in fact, there were numerous social changes and developments that created both the child- and the discipline of child psychology studying the child. He discusses the following as contributing to this cultural invention of the child: 1) the gradual division between the domains of work and family relegated women and children to non-work, domestic spaces 2) the distinct gender construction of men and women created distinct social perceptions of the genders and this division made women, by virtue of this gender construction, the natural primary caregivers of children and 3) because children were cared for at home and took on the gender qualities of the mother, they became perceived as innocent, pure and “sentimentalized” (Kessen, 1979, p.817). From these social shifts and developments, the definition of the child began with the “progressivist, sexist, and sentimental expectation of the larger culture standing by” (Kessen, 1979, p. 817). Taken together, Kessen effectively argues that young people are created by the society in which they are living.

The cultural foundations of child development have been supported by scholars in sociology. Within the field of sociology, a few childhood scholars have argued for a paradigm shift regarding the construction of childhood and arguably, an application to adolescence as well. Prout (2005) argues that this new paradigm should include the following themes: 1) childhood (adolescence) should be understood as a social construction 2) childhood (adolescence), as a variable of social analysis, can never be separated from other social variables and 3) childhood

(adolescence) and children's (adolescents') social lives and social relationships are notable of study in their own right. In this spirit, adolescence is a construct that is informed by diverse socio-cultural realities: the ways in which adolescence is understood and made meaningful is created and maintained by culture. This supports the idea that adolescents live within highly variable socio-cultural contexts. Adolescence is therefore not defined by age but rather by the socio-cultural meanings that this term invokes. This suggests that there is nothing intrinsic to human nature about psychosocial change during the adolescent period but rather, adolescence must be understood within the social context within which beliefs about adolescence are embedded.

### **Wrestling Realism and Nominalism**

My dissertation research involves adolescents and therefore the meaning of "adolescence" is implicit in this research. The philosophical perspectives discussed above have implications regarding the study of adolescents. The stance I take in my dissertation research is that adolescence is both biologically and socially constructed. In one sense, adolescence has a reality of its own, outside of how we think about it, with experiences and consequences for those in this time of development. In another sense, adolescence as a period of time, appears to be socially constructed and is dependent on how it's defined in a particular time and place. My positioning of this integrated understanding of adolescence is wrestled with in my dissertation by two methodological decisions I made. Firstly, my dissertation specifically focuses on adolescents which I have defined as ages 13-19 in order to focus on their potentially "distinct" experience that I believe to be over-shadowed within the term of AYA. I acknowledge that this grouping may create the perception of a homogenous entity, however, I have chosen to study this cohort of young people to narrow this gaze of inquiry specifically on adolescents. Secondly, the

interpretive orientation of applied hermeneutics implicitly acknowledges a non-realist perspective to understanding adolescents and facilitates openings for analysis apart from a developmental approach that has been historically used in psychosocial oncology research with adolescents. This methodological approach widens the interpretive frame for understanding the experiences of adolescents and permits such an exploration of experience not bound by developmentally normative constraints.

### **The Scientific Study of Adolescence**

The above ontological discussion begins to locate the contemporary study of adolescence. I discussed the alignment of a realist philosophical position with developmental psychology and how this has informed psychosocial oncology research with adolescents and young adults. How adolescents have been viewed historically also informs how they are currently conceptualized and the following sections will discuss the significant shifts regarding how adolescents have been understood and studied. Specifically, these sections will focus on pivotal events in developmental psychology that have contributed to the creation and understanding of ‘adolescence’.

Lerner and Steinberg (2009) outline three distinct phases within the historical scientific study of adolescence and adolescent development. In the first phase, initiated by the work of G. Stanley Hall (1904), research on adolescence was caught between a few tensions. During this time, theories of adolescence were either all nature or all nurture and most of the research on adolescence was atheoretical and descriptive (despite significant theoretical models of adolescence developing during this time). Theory and research were not congruent and a divide between scholars interested in basic developmental processes and practitioners engaged in applied work with adolescents, all acted to limit the growth of development in the study and

understanding of adolescence. The second phase of the scientific study of adolescence began in the early-mid 1970's and approached adolescence contextually and rejected a purely nature or nurture orientation. In this phase, there was an acute attention to the perception of the adolescent as a developmental system and the relationship between all levels of this system. This was a time of mid-level theory development and a closer relationship between theory and the study of adolescence (Lerner & Steinberg, 2009). Finally, the third phase of the study of adolescence involved a focus on applied inquiry. A focus in this phase is on the application of developmental science to inform practices and decisions of policy makers and clinicians to promote positive youth development for adolescents.

### **The First Phase of the Study of Adolescence**

Prior to the early 20<sup>th</sup> century, adolescence as a developmental period was not formally recognized. Although the first use of the term adolescence was offered in the 15<sup>th</sup> century (Muuss, 1990), the scientific attention towards this group of young people was not cultivated until the launching of the psychology of adolescence in the United States through the work of Stanley Hall (Kett, 2003).

#### **Stanley Hall**

In the early 1900s, Hall (1904) argued for the biological basis of adolescence and the significance of this period of time in development. Prior to this, adolescence hadn't been formalized as a distinct developmental time. Hall's work facilitated the emergence as 'adolescence'. In this way, adolescence has been referred to as an American discovery: an invention (Côté, 2014). Hall (1904) believed that all behavior could be linked to biological development and that adolescence was evolutionarily significant for human development. Hall extended the ideas of Haeckel (1868/1891) and advanced his idea of recapitulation.

Recapitulation was the belief that the development of the embryo goes through stages resembling successive adult stages in the evolution of the ancestors of a species. Hall extended these ideas from the prenatal period to apply to a theory of human development (Lerner & Steinberg, 2009). Hall also believed that the physical changes that accompanied puberty introduced character and personality traits in adolescents- regardless of their social or cultural context (Hall, 1904).

Adolescence then became understood as a distinct developmental stage and contained a universal essence. One of the most pervasive and enduring aspects of Hall's work is his theory of adolescent "storm and stress" (Hall, 1904). He argued that the psychological makeup of adolescents was distinct due in large part to the development of their mental operations being in continuous turmoil and conflict. He believed that adolescents universally experience emotional turmoil, emotional "storm and stress", and that this was a natural and expected part of their development. This construction of adolescence as a time of universal "storm and stress" has had a tremendous influence on the ways adolescents have been studied and how this time of human development has been understood (Côté, 2014). Conflict and turmoil were believed to be expected qualities of adolescence and this expectation has informed assumptions and stereotypes of young people and how they have come to be understood in their lives.

At the time of Hall's writings, not only were shifts happening in families and schools that impacted adolescents, but the industrial revolution and changes in agricultural society were displacing many young people who had previously held significant labour and household roles into urban centres. Adolescents increasingly began to be seen as a threat to social order and partly responsible for developing urban crime (Côté, 2014). They were beginning to be perceived as socially deviant. Not only then were adolescents acknowledged to occupy a distinct 'stage' in human development, they were also believed to be a social problem. This transition from the

historical perception of adolescent as ‘adult’ in the 19<sup>th</sup> century to adolescent as ‘problem’ has been a pervasive legacy of Hall’s and has a lasting impact on the public perception of adolescents (Côté, 2014).

Côté (2014) discusses that throughout the past century, the various ways that adolescence has been conceptualized has facilitated resulting social phenomena about adolescents. Between 1900-1960, he argues that following Hall’s theory and resulting social propagation of it, adolescents were perceived to be defiant and uncooperative. In response to the noted rise in urban crime, delinquency studies with adolescents flourished. Between 1950-1970, adolescents were believed to be in a state of rebellion. In this period of time, the perception of adolescence was that adolescents were believed to be challenging the social and role expectations placed upon them from modern societies and as a result protesting social conventions. Adolescents were believed to be threatening social and cultural cohesion (Côté, 2014).

Hall’s claim of the universality of adolescent turmoil has been challenged by other disciplinary scholars, most notably by the work of cultural anthropologist Margaret Mead. Mead (1928) studied adolescents in Samoa and observed that they did not experience the turmoil that Hall had described. This challenged the belief that adolescence is a time of natural rebellion and disputed Hall’s claims as the inevitability of emotional turmoil as a universal experience of adolescents. However, despite this challenge, the idea of adolescent “storm and stress” has remained theoretically dominant implicitly in the study of adolescents.

### **Socio-Cultural Shifts**

In addition to Hall’s contribution to the development of adolescent psychology, Hall also commented on the social expectations for adolescents and prescription of adolescent behavior. Hall (1904) believed that modern conditions were not congruent with the needs of adolescents

and that their rapid onset into adulthood introduced qualities such as precociousness, temptations, impulsivity, and distractions. Hall argued that modernity had created a problematic time for adolescents and that they should be provided a moratorium on adult responsibilities and offered opportunity to explore diverse interests and experiences (Kett, 2012). Hall's work was influential therefore in both formalizing the period of adolescence and also theorizing what makes this time of development unique.

Although Hall is credited with inventing adolescence, the shifts in the socio-economic context at the time of the onset of the 20<sup>th</sup> century in the United States, also created conditions for adolescents to have unique social needs and for them to be perceived differently than they had been (Kett, 2012). Throughout the 19<sup>th</sup> century, juvenile labour was well-utilized and normalized. Families required labour participation from all members of the family as soon as they were old enough to provide productive assistance and towards the latter half of this century, many families also depended on the earnings of their children in positions of un-skilled labour employment (Kett, 2012). However, youth labour dropped significantly from 1870-1930 as society became more industrialized. Adolescents were pushed out of the labour force by increased reliance on adult immigrants, valuing workers with completed education, and increased technological advancements in the labour context. Increasing numbers of adolescents began attending secondary education and this became a mass experience by the mid-twentieth century (Kett, 2012). Finally, in addition to changes in labour force participation, the gradual prolongation of schooling for adolescents, the experiences of adolescents became further attended to by the increased social attention to age introduced by these economic and social changes. Prior to the twentieth century, households were age-diverse and little attention was paid to one's specific age as labour was shared between the ages. Age was not a signifier of meaning

and thus did not set expectations for developmental experiences. However, chronological age became a guiding basis for classifying people and there became an enhanced age consciousness (Kett, 2012). Chronological began to then play a much more significant role in determining the expectations for groups of people (Modell 1989).

### **Peter Blos**

The deficit and biologically oriented approach to adolescence was a common thread in the first phase of the scientific study of adolescence. Peter Blos, a psychoanalyst, studied adolescents and early adolescent psychological development in the mid-twentieth century. His work was informed by decades of clinical experience with adolescents, specifically within the realm of juvenile delinquency (Muuss, 1980) but he articulates in his book *Adolescence* (1966) that his intention with his work is to develop a theory of typical adolescent development (adolescents in the Western world) and not of adolescent deviance. Blos was heavily influenced by the writings of Sigmund Freud and attributed much significance to oedipal phases of drive and ego development. Like Freud, he believed that the onset of sexuality began in early childhood and puberty continues psychosexual development whose antecedents began in early childhood (Blos, 1966).

Blos argued that adolescents are driven by their psychosexual development and that adolescence is therefore the process of psychological adjustment to biological and sexual maturation (Muuss, 1980). He conceptualized adolescence as the psychological processes of adjustment to puberty which provides a new drive and ego organization (Blos, 1966). Blos argued the personality development of adolescents, and typical adolescent development, depends upon a second individuation process where adolescents separate from their parents and familial love objects. This process provides the context of inner turmoil, external rebellion, chaos and

crisis that Blos believes is endemic for adolescents. This crisis and turmoil facilitates a developmental regression to childhood which Blos argues re-organizes and restructures the personality of adolescents allowing them to establish stability in their personality (Blos, 1979). Although his theory of adolescent development was not as widely accepted as others (Muuss, 1980), it continued to propagate the belief that adolescence was not just biologically-determined, but also contained universal and therefore natural, elements of turmoil and rebellion.

Taken together, the work of these developmental psychologists firmly located adolescence within a biologically-based perspective of development. Of greater concern and of more relevance to my dissertation research, is the continued tradition of a deficit view of adolescence being propagated. Throughout the first phase of the scientific study of adolescence, adolescents were perceived as deviant and in turmoil. These pivotal influences have had a lasting impact on how adolescents are perceived within society and constructed within research. While adolescence was recognized as a distinct phase of development, the qualities attributed to adolescents were informed by the values and beliefs of scholars who studied them. Côté (2014) argues adolescent “storm and stress” is one of the most enduring stereotypes produced by the social sciences.

### **The Second Phase of the Scientific Study of Adolescence**

Lerner and Steinberg (2009) propose that the second phase of the study of adolescence began in the late 1970s. They discuss that this phase specifically directed inquiry on adolescence and garnered multi-disciplinary research interest. Within this phase, adolescence was believed to be an ideal period of time for developmental science (Lerner, 2002). Adolescence was considered a context of interdependent biology and social context and was perceived to be an important window into human development (Lerner & Steinberg, 2009). Specifically, Lerner and

Steinberg (2004) identified four defining features of this phase: 1) the relationship between biological and social is interdependent in human development and this interdependence is the facilitator of development 2) the perceived agency of individuals promotes diversity in development 3) the plasticity assumed in adolescent development has shifted the focus in adolescent query from the problematic outcomes of adolescent development and 4) the belief that adolescence is the ideal time to study positive youth development.

Within this phase of inquiry, biopsychosocial models were proposed as models for adolescent development as they acknowledge that an adolescent's development must be contextualized by the different systems they are part of (Christie & Viner, 2005). This complex interplay between physical and psychological development and external and social factors creates the background for their psychosocial development. Developmental contextualism holds the belief that all organismic characteristics, as well as the whole organism itself, function in a bidirectional or reciprocal manner with all of the multiple contexts within which the organism is situated (Lerner, 1991; 1996). This model supports a transactional process of change between the organism and its context: each changes the other.

The strength of this kind of approach with adolescents is its focus on development over time, rather than concentrating on childhood and adolescence, and its appreciation of the contextual variability within human development which reduces the propensity to adopt a homogenized approach to the perception of adolescence. This framework has been extended and applied in a health context with the model of lifecourse health development (LCHD). An LCHD model attempts to capture the various influences on one's health through understanding of the contributions of multiple risk and protective factors operating throughout the lifespan. Specifically, this approach is developmental and addresses unique aspects of different times in

development (Halfon et al., 2013). In an article by Docherty et al. (2015), an LCHD framework was used specifically with adolescents with cancer. The health of adolescents with cancer was conceptualized as a composite of different biopsychosocial factors that required unique consideration and attention within their health trajectory.

### **The Third Phase of the Scientific Study of Adolescence**

Finally, Lerner and Steinberg (2009) discuss the beginning emergence of the third and current phase of the study of adolescence. Informed by the previous phase, the focus of research in this time is on the applied potential of developmental science. Developmental science is perceived as an opportunity to contribute to policy development and practice that promotes positive youth development and that directly impacts the wellbeing of adolescents. This phase values the integration of research into practice with adolescents.

### **An Entry for Applied Hermeneutics**

The historical representation of children in research is slowly changing. Children have been historically viewed as objects in research and subject to adult agendas and perceptions of childhood (James and Prout, 1997). Prout (2004) argues that within the study of childhood, there became a growing acknowledgement that the traditional ways of representing childhood were no longer congruent to the emerging understanding of childhood. There then began a development of new ways of speaking about and visually depicting children.

In comparison, although there have shifts in the understanding of adolescence, and attention to different versions of adolescence throughout history, the initial historical conceptualization has been enduring. What has been particularly damaging to adolescence is Hall's legacy of "storm and stress" and the assumed emotional lability of this group of people. The methodological choice for my dissertation study stems from the belief that adolescent

“storm and stress” has impacted the perceptions of adolescents both clinically and within research in oncology. Within the previous chapter, I discussed the pervasiveness of the conceptual frame of psychological distress to understand the experiences of adolescents diagnosed with cancer. As I noted, this frame is important in understanding this group of patients but is also narrowing regarding the full consideration of their experiences. The dominance of distress-related research in psychosocial oncology supports this assumption of the universal turmoil of adolescents. Adolescents are assumed to be distressed from the cancer experience and that this distress outweighs other aspects of their cancer experiences. Although research in psychosocial oncology has varied in its approach, most research has utilized quantitative measurement and has sustained a focus on psychological distress.

Within this chapter and the previous one, I have set the context for my methodological choice of interpretivism, and specifically of applied hermeneutics, to understand the topic of the posttreatment experiences of adolescents. Interpretivist methodologies can bring new understanding to this topic. Rather than arriving at a “true” understanding of a topic, hermeneutics supports arriving at new interpretations of a topic (Moules et al., 2015). This chapter has explored some epistemological concepts that have informed how adolescents have come to be understood socially and within psychosocial oncology research. I have outlined the various tensions that have informed how adolescence has been located philosophically, culturally, and historically. Within a hermeneutics-informed research approach, I am concerned not with supporting this dominant singular view of the adolescent experience but rather, creating space for multiple singularities to be understood. Ultimately, I am concerned with how adolescents are represented in psychosocial oncology research and through my dissertation I seek to re-present them in a different way. In the next chapter, I will discuss further the points of

resonance from philosophical hermeneutics and articulate how I have used this philosophy as a research approach to widen the understanding of what is known about adolescents who have had cancer.

## **Chapter Four: Hermeneutics as a Framework for Understanding**

### **Introduction**

My dissertation research is informed by the philosophy of hermeneutics. As clinicians, we often take up research topics because they matter within the lives of the patients/clients with whom we work. Within our practice lives, we are confronted daily with the complexity that resides within human life and in the practice context within which I am situated, the complexity that resides within disease and illness. Many of the experiences in health care that we witness or wonder about are beyond simple description: they are difficult to capture and difficult to measure.

The decision to pursue research informed by philosophical hermeneutics is a desire to open up possibilities for the meaning of a human experience to be more deeply understood. Conducting research in the spirit of philosophical hermeneutics is a commitment to the exploration of deep meaning: a commitment towards seeing a human experience as a whole and trying to peer behind aspects of phenomena that may have been concealed through historical transmission and dominant conceptualization(s) (Moules et al., 2015). Hermeneutics strives to decipher the obscure which hinders us from “going on” within a practice (Davey, 2017).

This chapter will first discuss hermeneutics broadly as a philosophy of understanding. I start here in order to establish the horizon for its forthcoming integration with my dissertation research. I then move on to discuss the specific philosophy of hermeneutics as understood and articulated by Hans George Gadamer (1960/2004) as it is his ideas that led me into further relationship with my research topic. I discuss core tenets of his hermeneutics philosophy which have informed how I have come to understand the topic of my research and have informed the

methodological decisions I have made throughout this study. Finally, I then discuss how I am applying Gadamer's philosophical ideas specifically within the context of my research.

This chapter is the third chapter laying out the foundation of my study. Within the previous two chapters, I outlined ideas and concepts that have contributed to how the topic of adolescents' posttreatment experiences have been traditionally understood. I also discussed what might inform how this topic has been understood. Within this chapter, my intention is to align my research topic with a hermeneutic approach to understanding.

I have used the phrase "framework of understanding" here as opposed to "methodology" to orient this chapter. Engagement with language is important within Gadamer's philosophy of hermeneutics and is critical to hermeneutic inquiry (Moules et al., 2015). The term "framework" suggests a structural map which is more congruent to hermeneutics than an inflexible and established structure which is suggested by the term "method". Gadamer (1960/2004) challenged immutable systems of knowing and the reliance on a rigid, pre-established approach to understanding and knowledge-building. A map, although depicting the terrain at hand, invites exploration and multiple routes to move through the terrain and access the destination. This is similar to the event of understanding in hermeneutics: the pursuit of a topic travels us through different terrain.

### **History and tradition**

Understanding, within Gadamer's hermeneutics, comes from somewhere: topics carry a historical legacy and a tradition of how they have come to be understood. Gadamer (1960/2004) used the term "historically effected consciousness" to refer to the way our historical experiences affect our current perceptions and interpretations: understanding is "entangled in the context of historical effect" (Gadamer, 2004, p. 234). Inquiry informed by philosophical hermeneutics

demands attention to the history of a topic. “Part of real understanding, however, is that we regain the concepts of a historical past in such a way that they also include our own comprehension of them” (Gadamer, 2004, p. 382).

Throughout the previous two chapters, I have discussed a history of adolescents’ posttreatment experiences. I have suggested that the topic of posttreatment experiences has been historically narrowly explored and the meaning of these experiences as lived by adolescents has not yet been well developed. Both the limited examination of posttreatment as a period of time, and the historical perception of adolescents more generally, have contributed to limited inquiry on this topic.

Adolescents’ posttreatment experiences have been primarily understood as psychological distress. The term, “distress”, has become part of the tradition of understanding of this topic and the transmitted meaning of posttreatment experiences. The philosophy of hermeneutics highlights the significant role of tradition at play in all understanding. Understanding is embedded in, and informed by, tradition (Moules et al., 2015). In this way, tradition conditions our understanding as what constitutes this tradition is not always recognized or acknowledged. Gadamer argued that tradition is not something that we can consciously evaluate to decide whether we will accept or reject. Rather, we “stand in traditions, whether we know these traditions or not” (Gadamer, 2001, p.45) and therefore, they impact our understanding of phenomena. The idea of being addressed which I discussed in the introductory chapter, confronts this tradition and evokes a new possibility to understand a topic differently: to stand between the strangeness and familiarity of a topic (Gadamer, 2001). This dissertation research offered me the opportunity to confront the tradition and legacy of distress as constitutive of understanding of posttreatment experiences and to explore other ways of understanding this period of time.

### **A Different Way to Understand**

Hermeneutics offers a different way to understand human experience. It's this different way of understanding that drew me to hermeneutic inquiry for my dissertation research.

Gadamer (1996) challenged the dominance of positivism and the scientific method within epistemological contexts such as health care. He argued that "method" is not the only way knowledge should be actualized in the humanities and social sciences, and I suggest, in any context that involves the human experience. His work advocates for an enlarged context of human understanding that includes equal space for both scientific knowledge and other ways of knowing (Moules et al., 2015). His argument underpins the diversity of human experience and the complexity involved in arriving at understanding and meaning within human contexts.

Honouring an interpretive approach to understanding human experience resists the inclination to explain and to generalize. Instead, it gives voice to a topic and opens up possibilities of understanding to topics that have been often perceived as closed (Moules et al., 2015).

Gadamer (1996) calls for the renewed relationship between inquiry and bodily experience. This accounting for one's individual experience moves us beyond collective data and instead brings us closer to understanding the human within/through illness. I have argued that inquiry into adolescents' posttreatment experiences has become narrow and instrumentalized. Much of the extant research has been from a quantitative paradigm and the impact of this has created a limited methodological approach to this topic. In efforts to refine understanding, we have reduced its complexity. Simply, understanding of this topic has been limited by method. Plato (as cited in Gadamer, 1996) articulates a distinction between two different conceptualizations on what is measured within measurement. One is a measure against imposed criteria: an application of measure. One is measuring against criteria generated by the object

itself. It is this second differentiation of measure that applied hermeneutics hopes to harness. Instead of responding to uncertainty with distance, objectivity and control, hermeneutics seeks to understand and inquire into the strangeness and uncertainty (Holroyd, 2008).

### **Interpretation as Understanding**

Hermeneutics has a deep epistemological history. Beginning in the 17<sup>th</sup> century, hermeneutics was used within biblical and theological textual interpretation as a means to illuminate, interpret and bring forth meaning (Moules, 2002). Hermeneutics is derived from the Greek verb *hermeneuein* which means to say or interpret and also from the name *hermeneus* which refers to Hermes, the playful and mischievous Greek messenger of the gods. Hermes was responsible for bringing messages to humans from the gods and in so doing, embodied interpretation as he was bringing the unknowable into a form that humans could understand (Moules, 2002). Although the disciplinary origins of hermeneutics were theological, there is a growing tradition of hermeneutics in qualitative health research as it offers a way to understand human experiences within illness and health (Austgard, 2012).

Hermeneutics rests within the desire to understand the conditions that make understanding possible (Gadamer, 1960/2004). It brings meaning forth within dialogical and textual interpretation and makes interpretation explicit in understanding. Specifically, hermeneutics is the philosophy, practice, and theory of interpretation and understanding in human contexts (Moules et al., 2015). In health care, interpretation is endemic to practice: we interpret patients, their illnesses, and the impact of illness on the biopsychosocial context of their lives. Like health care practice, hermeneutics values particulars and resists universals (Gadamer, 1960/2004). Moules et al. (2013) suggest that oncology practice is itself hermeneutic as each patient, each case, challenges what is known and is a particular of a topic to be understood. In

philosophical hermeneutics, “interpretation moves to represent the particular and to bring it to presence, not essence” (Moules, 2002).

Within health care practice, attention to the particular is often challenged by the work of universals: universal diagnoses, established treatment protocols, and prescriptions of the illness experience. However, illness is lived and experienced by each individual with an illness. “We say that something is a case of a regularity or a principle” (Gadamer, 1996, p. 95) and we rarely acknowledge that cases are of value when irregular or contrasting a principle. Gadamer (1996) argues that in medicine a “case” of a patient is often a matter of abnormality or disfunction- a condition of the removal of the case from the surrounding social world. Yet these cases, and understanding of these particulars, facilitate a greater depth of understanding of the complexity of human experience of living with illness and health. David Jardine (2000) writes, “hermeneutic inquiry is thus concerned with the ambiguous nature of life itself. It does not desire to render such ambiguity objectively presentable (as if the ambiguity of life were something to dispel, some 'error in the system' that needed correction) but rather to attend to it, to give it a voice” (p. 120).

### **Truth in Hermeneutics**

Hermeneutic inquiry therefore strives to preserve a living topic and to bring forth meaning of human living (Moules et al., 2015). Interpretive understanding allows us to grasp, although not in their totality, un-measurables of human experience that are beyond descriptive understanding. Davey (2006) uses the term hermeneutic differentials to refer to these interpretive spaces that exist within one’s understanding of a topic. However, within the philosophy of hermeneutics, understanding is always partial as a topic can never be understood in its totality and can not be fully known. We work within research inquiry to penetrate the matter but the

matter is always greater than what can be seen and explored (Moules et al., 2015). Hermeneutics responds to the vastness of topics by attempting to see and understand aspects of them in new and different ways. Philosophical hermeneutics contends that the vitality of understanding actually depends on difference (Davey, 2006): trying to understand this difference expands understanding of a topic to be understood.

Within hermeneutics, understanding has movement. I discussed within my introductory chapter the concept of “being addressed”: being addressed by something as an un-settling of what is understood. Hermeneutic understanding is displacement: being addressed displaces our understanding. “Truth” in hermeneutics therefore requires the capacity for movement. Within the hermeneutical experience, truth is not absolute or eternal. Rather, it is contextual, situated, and is arrived at from an understanding of meaning. Aletheia is a Greek term meaning the “event of concealment and unconcealment” of a topic (Caputo, 1987, p. 115). This refers to the idea that a topic can never be fully known in its entirety. While inquiry can unconceal and enliven some aspects of a topic, this unconcealing, also conceals: as something is revealed, something further is concealed. Within this way, aspects of truth are revealed, but we can never arrive at a full and complete truth of a topic. Therefore, the process of understanding is never complete as the topic of inquiry will always be greater than one’s understanding of it. The work of hermeneutics is the work of aletheia: to enliven aspects of a topic that may be forgotten or not seen (Moules et al., 2015). This is significant for topics like posttreatment experiences that have become essentialized and aspects of it have become persistently concealed.

### **Gadamer’s Philosophy of Hermeneutics**

Hermeneutics has been interpreted in different ways over the past two centuries. My dissertation is in the approach taken by Hans George Gadamer (1900-2002) and the sections

below will offer articulation of some of the core tenets of Gadamer's philosophy of hermeneutics.

### **Hans George Gadamer**

Gadamer is considered one of the most prominent figures of 20<sup>th</sup> century philosophical thought and his work, *Truth & Method* (1960/2004), a significant work of the last century (Grondin, 2003). Gadamer articulated hermeneutics as a mode of understanding and discussed the work of hermeneutics as revealing the conditions under which understanding occurs (Gadamer, 1960/2004). Like Heidegger, Gadamer's philosophy of understanding is also ontological. He regarded understanding as the basic movement of human existence and that our engagement with the world is not just theoretical but practical. As I will discuss below, Gadamer places much more primacy on language and conversation than Heidegger's (1927) articulation of hermeneutics. Gadamer's philosophy of hermeneutics has been integrated into a tradition of hermeneutic thinking that has formed the basis for applied hermeneutics as a research approach (Moules et al., 2015). I have selected a few of Gadamer's dominant ideas discussed below which have informed the methodological decisions I have made in this study and ones that I will take up within the following sections on application in the context of my research.

### **Fusion of Horizons**

Within philosophical hermeneutics, one is situated within a historically constituted horizon of understanding. This horizon is a range of vision that includes everything that can be seen from a unique vantage point (Gadamer, 1960/2004). This horizon includes assumptions, ideas, values that condition how we look at the world (Moules et al., 2015): horizon is a metaphor for how phenomena are perceived and interpreted. Although the term "fusion" may invoke the sense of complete incorporation, Gadamer used this term to refer to a combining of

different vantage points that retain elements of each horizon. Although provisional, this fusion creates a new perspective of understanding that is different and more expansive than what could be offered through each individual horizon alone (Moules et al., 2015). In this way, we come to recognize that our horizon is part of a larger transmission of meaning within the understanding of something.

Gadamer (1960/2004 ) initially used this phrase to refer to the integration of the present horizon with the past horizon- the past horizon informs the present horizon and in turn the present informs a re-interpretation of the past. He then extended this phrase to refer to both engagement with texts as they hold a view of the past and also to conversation with another (Moules et al., 2015). This idea has significant application to research inquiry. We bring a horizon of understanding into the research that becomes fused with the participants': we come away from the research process with an enlarged understanding. This fusion also occurs through the reading of literature and of engagement with transcripts as texts. Each of these sites of fusion contributes to a widening understanding of a topic of inquiry.

### **Conversation**

Central to Gadamer's philosophy of hermeneutics is his belief in understanding as dialogical (Gadamer, 1960/2004). Within dialogue, understanding develops within the back and forth dialectic of question and answer: this dialectic, is a necessary context for understanding. Dialogue actualizes the meaning of a subject: it extends meaning beyond what is captured by words alone. "Questioning opens up possibilities of meaning, and thus what is meaningful passes into one's own thinking on the subject... questions always bring out the undetermined possibilities of a thing (Gadamer, 2004, p. 383).

Philosophical hermeneutics resists containment and categorization (Gadamer, 1960/2004). Within the context of conversation conceptualized by Gadamer's philosophy of hermeneutics, meaning is not reduced to linguistic selection. In other words, meaning created through dialogue is actualized through language- not created by it- thereby surpassing the linguistic boundaries of the word that can constrain understanding (Davey, 2006). In this perspective, language is not representational of meaning: it actualizes meaning. Wittgenstein (1953) wrote, "One thinks that one is tracing the outline of the thing's nature over and over, but one is merely tracing round the frame through which we look at it" (p. 114). In hermeneutics, this frame is poked and provoked through the exploration of language and dialogue. Hermeneutics considers "what is said, what is uttered, but at the same time what is silenced" (Grondin, 1995, p. x). In this way, through dialogue, hermeneutics disrupts a clear narrative of a topic as it confronts the context of language and peers behind it (Moules et al., 2015).

### **Movement as Play**

Hermeneutics maintains that a topic is at play: a topic has a living meaning and seeing the topic in its complexity requires keeping its vitality at play. Although dialogue invites us into the flux of play, a topic remains at play regardless of our involvement in it and the interpretations we make of it (Moules et al., 2015). Within hermeneutical understanding, "the primacy of play over the consciousness of the player is fundamentally acknowledged" (Gadamer, 2004, p. 109). The nature of flux inherent in play bears the risk of being reduced if topics become essentialized: with efforts to remove this flux, the holism of a topic is reduced. As I have discussed, the manner in which the topic of posttreatment experiences has been pursued, has limited understanding of the breadth of experiences surrounding a posttreatment time for adolescents. Within these efforts to refine understanding, there has been little acknowledgement of the "flux" that surrounds it.

Within my dissertation research, I wanted to both expand and stretch established tacit understandings of adolescents' posttreatment experiences in order to preserve and understand the living flux of this topic. Caputo (1987) writes "hermeneutics always has to do with keeping the difficulty of life alive" (p. 2).

## **Prejudices**

The term "prejudices" refers to prior understandings, or prejudgements, that we hold about a topic. Prejudices are initial interpretations that are operant in our understanding and created from history, tradition, and language: the social context within which we are embedded. In his philosophy of hermeneutics, Gadamer (1960/2004) believed that prejudices are essential to the facilitation of understanding as they create an initial interpretation of a topic. Unlike the negative connotation usually invoked by this term, Gadamer maintained that held prejudices move the process of understanding along. We come to something with prejudices but through conversation, these prejudices begin to reform and potentially become replaced as understanding of a topic enlarges (Moules et al., 2015). In the context of research inquiry it is therefore not possible, or even desirable, to bracket these preunderstandings as required within a more descriptive phenomenology. Gadamer (1960/2004) argued that prejudices have to be provoked to be suspended and that dialogical encounters can provide this provocation. These prejudices can be explored interpretively to avoid obstructing a path of understanding (Grondin, 1995). Throughout the conduct of this study, I have used prejudices to orient analysis throughout this study. I have paid attention to the prejudices I held about the topic of my dissertation, ones held by others, and ones that changed for me through the life of this study. These reflections informed my offered interpretations within the following chapters.

## **Application of Hermeneutics**

Gadamer's philosophy of hermeneutics is not a methodology or method: instead, it is a way to understand (Moules et al., 2015) and perceived as a mode of being (Davey, 2006). Although this leaves no universal principles of hermeneutics or criteria for research inquiry, it is still methodical (Grondin, 2003; Moules et al., 2015). The previous sections outlined Gadamer's philosophy of hermeneutics and contextualized the rationale for the selection of this "framework" for my dissertation research. The following sections of this chapter offers discussion on how I applied these philosophical ideas concretely to the conduct of researching the topic of my study and how they helped me to clarify the interpretive conditions of understanding of my research topic.

### **Research Questions**

Within the conception of my dissertation research, I held the following beliefs: posttreatment experiences are predominantly understood and historically defined within the framework of psychological distress and that this theoretical dominance has had implications for understanding the holistic experiences of adolescents who have completed treatment for cancer. Therefore, the following research questions guiding this study are: 1) How might we understand how adolescents experience a posttreatment period of time following the completion of cancer treatment? 2) How might we understand the meaning adolescents make of this posttreatment time? As truth in hermeneutics is always partial and fallible, these research questions are written to reflect this tentativeness in hermeneutic understanding.

### **Sample and Study Participants**

The work of hermeneutics as research is the attention to, and enlivening, a topic. Within hermeneutics-informed research, the topic remains the focus of inquiry. Through the words of

the research participants, the “matter” (the Sache) is revealed (Moules et al., 2015). It is therefore not the single experience of the participant that is pursued, but rather, each participant’s engagement with the topic that receives interpretive attention. Purposive sampling is therefore well-aligned to a hermeneutics-informed study as participants are those that are best situated to speak about the topic and contribute their experiences to a deepening understanding of the topic of inquiry (Moules, 2002). In this study, thirteen Canadian adolescents aged 13-19 participated (sample briefly described below). Hermeneutic inquiry is not validated by sample size. Instead, sample size is assessed by the depth and completeness of interpretations made from participants’ experiences with a topic that extend understanding of the topic (Moules, 2002). Within this study, recruitment stopped once I stopped being surprised or struck by instances and particulars in the data.

Participants were recruited from the pediatric oncology program at British Columbia Children’s Hospital by oncology healthcare clinicians. Clinicians invited eligible adolescents to participate in the study if they met the criteria described below. Eligible adolescents and their parents were provided with a short written summary of the study (Appendix C). Institutional ethics approval was obtained from the University of British Columbia Children’s and Women’s Research Ethics Board.

All participants in this study were diagnosed with some form of cancer and all had been treated with chemotherapy. Being treated with chemotherapy was included as a qualifying criterion in this study to ensure that participants received an active and typical course of cancer treatment. This is a distinct pathway from those adolescents diagnosed with cancer who require only surgical intervention or who do not require any treatment following a cancer diagnosis. I made this decision to ensure that participating adolescents would have spent some time within

the experience of “cancer” and may have experienced some impact from cancer that I discussed within the introductory chapter. Specifically, participants who met the following criteria were invited to participate in this study: 1) to be between the ages 13-19 at the time of their study participation 2) to have completed treatment between 0-18 months prior to their study participation 3) to have received treatment for a primary cancer as opposed to treatment for a relapse of cancer and 4) to not have a disease that has become palliative. Assent was obtained from each participant and consent obtained from a parent or guardian prior to the onset of their participations. Sample assent and consent forms are provided as Appendix A and B respectively. Participants also completed a demographics form at the time of their research interview (Appendix E).

I have described the composition of the sample in this study with their demographics below in order to highlight the sample as composed of multiple singularities. The participants' names have been changed. Within hermeneutics-informed research, participants are neither aggregated nor are conceptualized as narratives whose individual details are preserved for analysis and examination. Individual participants are perceived as singularities: each contributes something unique and distinct to the phenomenon of inquiry. Also, in line with these philosophical underpinnings, the narratives of the participants' that have been included within my offered interpretations have not included their names. Hermeneutics selects participants for inquiry who can best inform the topic that is being explored. Within this approach to research, narratives are not preserved in order to understand the experiences and perspectives of individual participants, but rather, how they can inform the topic that is being studied.

### **Participant 1**

Ben is 17 years old and is a self-identified male. He lives with his mother, father, and two older siblings. He was born in Canada. He was diagnosed with Lymphoma at age 16 and had completed treatment three months prior to his participation in the study.

### **Participant 2**

Alex is 14 years old and is a self-identified female. She is Chinese- Canadian and lives with her mother, father, and younger sister. She was not born in Canada. She was diagnosed with Acute Lymphoblastic Leukemia (ALL) when she was 11 years old. She had completed treatment two months prior to her participation in the study.

### **Participant 3**

Lisa is 16 years old and is a self-identified female. She was born in Canada. She lives with her mother and grandmother. She was diagnosed with a sarcoma when she was 14 years old. She had completed treatment eight months prior to her participation in the study.

### **Participant 4**

Matt is 17 years old and is a self-identified male. He was born in Canada. He lives with his mother, father, and an older sibling. He was diagnosed with a brain tumour when he was 16 years old. He had finished treatment six months prior to his participation in the study.

### **Participant 5**

Tom is 16 years old and is a self-identified male. He was born in Canada. He lives with his mother, father, and a younger sibling. He was diagnosed with lymphoma when he was 15 years old. He had finished treatment five months prior to his participation in the study.

### **Participant 6**

Ryan is 17 years old and is a self-identified male. He was born in Canada. He lives with his mother and father. He was diagnosed with Acute Lymphoblastic Leukemia when he was 14 years old. He had finished treatment seven months prior to his participation in the study.

#### **Participant 7**

Liam is 16 years old and is a self-identified male. He is Chinese- Canadian and lives with his mother and sister. He was born in Canada. He was diagnosed with lymphoma when he was 15 years old. He had completed treatment eight months prior to his participation in the study.

#### **Participant 8**

Felix is 18 years old and is a self-identified male. He was born in Canada. He lives with his mother and grandparents. He was diagnosed with a brain tumour when he was 16 years old. He had completed treatment twelve months prior to his participation in the study.

#### **Participant 9**

Amanda is 18 years old and is a self-identified female. She was born in Canada. She lives with her mother, father, and older sibling. She was diagnosed with Acute Lymphoblastic Leukemia (AML) when she was 15 years old. She had completed treatment seven months prior to her participation in the study.

#### **Participant 10**

Ian is 16 years old and a self-identified male. He was born in Canada. He lives with his mother. He was diagnosed with lymphoma when he was 15 years old. He had completed treatment four months prior to his participation in the study.

#### **Participant 11**

Jacob is 15 years old and a self-identified male. He was born in Canada. He lives with his mother and older sibling. He was diagnosed with a sarcoma when he was 13 years old. He had completed treatment five months prior to his participation in the study.

### **Participant 12**

Andy is 16 years old and a self-identified male. He was born in Canada. He lives with his mother, father, and two older siblings. He was diagnosed with Acute Lymphoblastic Leukemia (ALL) when he was 13 years old. He had completed treatment eight months prior to his participation in the study.

### **Participant 13**

Sean is 14 years old and a self-identified male. He was born in Canada. He lives with his mother, father, and two younger siblings. He was diagnosed with lymphoma when he was 13 years old. He had completed treatment four months prior to his participation in the study.

### **Dialogue as Data**

Conversations conducted in the spirit of Gadamer's hermeneutics are generative as understanding that develops is not limited to either of the respondent's previous understandings but reaches beyond where the researcher and participant had begun in the conversation (Gadamer, 1960/2004). Conversations facilitate the fusion of horizons previously described. The research interview is a unique kind of conversation and although due to the power differential between the researcher and the participant it can't be a genuine conversation in the spirit that Gadamer intended conversations to be, the research interview can still be conducted with genuineness (Binding & Tapp, 2008). Gadamer proposed genuine conversation as a distinctive mode of understanding in the human sciences. He described a genuine conversation as one that is open to the other, offers intentional questioning, and makes space for the possibility of new

understanding to take hold (Binding & Tapp, 2008). Within each interview, I intentionally occupied an empathic stance. I was present, attentive, and self-reflexive. I listened deeply and responsively to what participants said and what they decided to speak about.

Interview questions are also generative. Although I used an interview guide (Appendix D), questions that I asked veered from this guide in order to keep the interview oriented around the topic of posttreatment experiences of the participants. In this way, each interview was different. Questions are significant in philosophical hermeneutics (Moules et al., 2015). Hermeneutic inquiry uses questions to create a new path of understanding and to unearth aspects of understanding that are hidden. My hope with the questions I asked was to understand the rich horizon of the experiences of the topic of posttreatment as lived by adolescents who had been diagnosed with cancer. The prejudices and phronesis that I carried as a clinician informed the dynamic interplay between the questions I asked and the interpretations I made. In addition to the interview, demographics of each participant was also self-completed by the participant at the beginning of the research interview (Appendix E).

The interviews occurred at the time of participants' choosing. Some occurred during the week, others on the weekend. Some took place at the hospital and others took place in the participant's home. I tried to accommodate their preferences for timing of the week, timing of the interview within the context of their posttreatment life, and location.

### **Data Analysis**

In adopting a hermeneutics-informed approach to research, data analysis is synonymous with interpretation: hermeneutical understanding is interpretation (Moules et al., 2012). Being addressed by a topic in hermeneutics is already beginning to understand a topic in a new way and analysis occurs throughout the conduct of a hermeneutics-informed study. Within the analysis of

the dialogical data of this study, I read each transcript numerous times to get a sense of the data. Transcripts are considered living interpretations (Moules et al., 2015) and each reading of them potentially offers a new portal to understanding the data. Within this reading, I made notes of these beginning analytic interpretations. Within these transcript readings, I paid attention to what grabbed my interest and what displaced my understanding: what surprised me. Hermeneutics attends to exemplars in the data- particulars that will advance understanding of a topic and I noted what I perceived to be exemplars. However, I kept the topic in mind when engaged by these interpretations and tried to keep the topic in mind throughout the process of analysis.

Moules (2016) discusses that there is a “hermeneutic wager to take a risk” (p. 1) within the following of leads and the commitment to their exploration and I remained self-reflexive regarding why I was following certain leads. Gadamer argued for significance over objective textual meaning and these significant particulars in the data led me into dialogue with them. In Gadamer’s (1960/2004) conception of hermeneutics, one is not just in dialogue with another but one is also in dialogue with the text. Dialogical engagement with the transcripts as text offered me the opportunity to explore what struck me. Throughout my readings of the transcripts, I asked questions of the data in efforts to see it from a different vantage point. These questions included:

- i) What is standing out for me?
- ii) How does this change my understanding of the topic? Why?
- iii) How might this align with my research topic?

I was attentive to what these questions introduced for me and I recorded my reflections and ideas to be used in my interpretations. In this way, I was in conversation with the topic. These texts opened up possibilities to understanding through entering into dialogue with them (Davey, 2006) and this dialogue was ongoing throughout the analysis. Reflexive questioning occurred throughout the study and generated an audit trail that documented the research process.

One of the epistemological underpinnings of data analysis in hermeneutics is the recursive nature of data analysis. Analysis involves the movement between the whole and parts of data by the researcher in order to better see and understand the complexity of a topic. Meaning presents as the researcher and text (both original and interpretations) continue this established dialogue (Moules et al., 2015). This dialogical engagement with the topic facilitates moving in and out of the hermeneutic circle. The hermeneutic circle refers to a conceptualized process of interpretation involving moving between particulars in the data and the whole of the data, between the individual participant and the sample, and between what is “familiar and what is strange” (Gadamer, 1960/2004; Moules et al., 2015). Conceptually entering the hermeneutic circle began with interpretive memo-writing that occurred throughout my readings and re-readings of the transcripts and the contextual notes I wrote after each interview. These notes included descriptions of: my perception of participants’ affect throughout the interview and any changes in affect that occurred, impressions of their comfort level throughout the interview, any points in the interview that felt uncertain or unexpected, and any analytic impressions I was beginning to make. Practically, moving in and out of the hermeneutic circle required me to move back and forth between the transcripts, my beginning interpretations, my memos, and literature and philosophy that were supporting the shape of my developing interpretations.

Moving through the process of memo-writing allowed me to develop interpretive conjectures that were created from participants’ words and ideas. These beginning interpretations are small chunks of interpretive writing that become further developed as the interpretations deepen and hold a plausible connection to the topic (Moules et al., 2015). These interpretive conjectures – things that caught my attention, allowed me to continue moving conceptually through the hermeneutic circle with further developed interpretations of particulars in the data.

This allowed me to assess their value and “validity.” In efforts to maintain the flux of this topic, within my analysis, I did not break up the data into final themes or use any coding software. This allowed me to avoid reducing the data and instead to engage with both the particulars of the data and their location within the data as a whole. Interpretive analysis in hermeneutics is not trying to strip an aspect of data out of its context- rather seeing the context that locates the particular will widen understanding of the topic (Moules et al., 2015). Although I did think conceptually in themes during the process of developing interpretive conjectures, themes were the beginning component of my analysis and not an outcome of analysis. These themes offered an opportunity to explore certain particulars in the data further and to interpret their meaning. However, I quickly realized that theming the data was removing its context: I felt that it was actually eroding the data as it was stripped from its context. As I progressed in my analysis, it became easier for me to not theme the data but rather, to note what struck me and then to write an interpretation.

I deepened my developing interpretations through interpretive writing. Interpretive writing is endemic to hermeneutic analysis and it allows the integration of both textual details and developing interpretations into a meaningful whole (Moules et al., 2015). Interpretive writing brings “the topic to life in language” (Moules, 2002). It opens up possibilities for new understanding of a topic and continues to refine and develop interpretive understanding. Within my developing interpretations, I remained attentive both to language and to what would allow me to further extend the meaning of posttreatment experiences. When I was confronted by words in the transcripts or in my developing interpretations that struck me with their selection in a certain context or by words whose holistic meanings I realized that I did not really know, I explored these words further to understand their historical, and perhaps hidden, meanings. Some of these meanings acted as springboard for analysis. I was also really attentive to thinking about

what lines of philosophical or theoretical inquiry might extend further understanding of my topic. In this way, I dialogued with both philosophy and literature throughout this analysis and used their ideas to develop new aspects of a topic to be seen and understood. In hermeneutic inquiry, the researcher may turn to the literature to seek help in understanding (Jardine, 2006), and consequently this literature aids in analysis and in fact becomes data. Literature is not used to support, verify, or confirm findings, but rather to further explore, understand, and find meaning and history to what it is the participants have to say about the topic. These interpretations were developed, revised and refined as I continued to move in and out of the hermeneutic circle. They were also revised when I noticed I began to explain- rather than to offer an understanding.

What follows in the next chapters are my “findings”- my interpretations. I believe that these interpretations strengthen and further understanding of the posttreatment experiences of adolescents. I also believe that these interpretations reflect the fusion of horizons in the spirit that Gadamer intended as they are interpretations that extended beyond the prejudices of posttreatment held by myself or by the participating adolescents. Within the interpretations I have offered, the intention is not to generalize, and I acknowledge that each adolescent is different as they navigate their diagnosis and move through cancer in a unique way. Hermeneutics is dialogical and in addition to the dialogues I engaged in as described within a previous chapter, I also realized that I was dialoguing with many of the adolescents I have met previously. I have held these adolescents in my mind and have utilized them as conversation partners within this analysis and writing.

### **Trustworthiness**

Arriving at interpretations is a rigorous practice that is intentional and reflexive (Moules et al., 2015). Although there is not one final interpretation of a text, we hold the responsibility to

be accountable to our interpretations and to preserve the sense that we have actualized the data in believable ways and offered the best interpretations. Denzin & Lincoln (2011) argue for the necessary consideration of rigour and credibility to ensure the quality of the interpretive approach. Qualitative research is assessed with different criteria of rigour and in hermeneutics research, rigour can be understood as trustworthiness. Although there is not one “true” interpretation that is “revealed” from the data, some interpretations ring more true than others (Moules, 2002). These interpretations do not close the topic but open up the topic for further exploration and interpretation and deeper understanding.

Interpretations, although not entirely subjective in hermeneutics research, are those of the researcher. To maintain a commitment to the trustworthiness of my emerging interpretations, I dialogued with others about these interpretations. I shared these interpretations with experts in both social sciences and oncology (medicine, nursing and social work). This dialogical process allowed me to open up my interpretations and provided opportunity to confront me with the prejudices, history and assumptions that may have narrowed how I was understanding the changing nature of this topic. Hermeneutics does not use member-checking as encouraged by other qualitative methodologies (Denzin & Lincoln, 2011). Member-checking is not useful in this interpretive context as interpretations of the topic are not representations of participants’ narratives. Gadamer offers a definition of harmony which conceptualizes the integration of understanding... “the harmony of all details with the whole is the criterion of correct understanding... failure to achieve this harmony means that understanding has failed”. Harmony is the coming together of differences that align in a meaningful whole. This integration enlarges what is known by weaving separate elements into a harmonious union (Gadamer, 1989, p. 291, as cited in Moules, 2002). The interpretations that follow attempt to illustrate the harmony of the

experiences shared with me by adolescents treated for cancer.

### **Conclusion**

In this chapter, I have offered an overview of philosophical hermeneutics as the “methodological” context within which my dissertation research is situated. I have discussed hermeneutics as a mode of understanding broadly and then more specifically with how Gadamer has taken up hermeneutics. My dissertation research is informed by tenets of Gadamer’s philosophy of hermeneutics and I have provided some discussion of these core ideas. Within the discussion and articulation of these ideas, I argued for my selection of hermeneutics as a well-aligned approach to further understanding on the topic of the posttreatment experiences of adolescents treated for cancer. I offered that the value of this framework of understanding to topics that have become reductive or essentialized by dominant methods of understanding and discourses, opens space for the living nature of the topic to be seen and potentially differently understood.

The following chapters will present my interpretations of adolescents’ posttreatment experiences. Although referred to as “findings” within other methodological contexts, my use of the term interpretations acknowledges both the authorial responsibility for these interpretations and the acknowledgement of the potential fallibility of understanding. The voices of adolescents that have contributed to widening understanding of this topic are both directly and indirectly dialogically reflected in the chapters that follow. These three chapters are written around dominant exemplars within the narratives of adolescents in this study: the body, liminality, and relational disconnection/connection. These are an offering of how I have come to understand the experiences of adolescents within a posttreatment period of time.

I titled this dissertation, *Cancer as interruption*, in advance of analysis of this study but “interruption” has become a significant exemplar of adolescents’ experiences: aspects of their life and body interrupted from cancer. The etymological origin of “interruption” is from the 14<sup>th</sup> century Latin term *interruptionem* which means a “breaking off” (Online Etymology Dictionary, 2021). Cancer intervenes into an adolescent’s life and breaks their life off onto a different path. They are broken off from their bodies and from their lives as they navigate the barriers and obstacles that cancer presents. This research enquires into these spaces. My hope is that these interpretations offer a resonance that enhances our understanding of adolescents within the context of cancer and their posttreatment experiences.

## **Chapter Five: The Body**

### **Introduction**

This chapter explores adolescents' experiences with their body following the ending of cancer treatment. The body, so central in the treatment of cancer, often becomes relegated to, and taken over by, the domain of treatment and to those providing the treatment. The confrontation with one's body, and the experiences of physicality after treatment, often leaves adolescents re-experiencing their bodies, or meeting their bodies again in a different way, after cancer treatment ends. The body often comes back into view for many adolescents after the ending of treatment and the meaning of living within a body treated for cancer after treatment has ended is the focus of this chapter.

### **The Body Treated for Cancer**

Cancer treatment on a body is aggressive. It seeps into the body, it burns the body, it creates scars on the body in its removal of parts of the body. In this perspective, treatment is embodied: it becomes part of the body. For many, prior to the onset of cancer, the body is not given extensive detailed and systemic consideration. It is often offered focus in times of physical strength and wellbeing and alternately in times of pain and physical malaise. Within the space between these polarities, the body is not often recognized and seen. For many, prior to the spread of disease, the body is not known.

For an adolescent however, the body is often known. The body is considered, examined, judged, criticized, and subjected to efforts of change. The body is held in immediate view. Adolescents are confronted daily with their bodies and subject their bodies to scrutiny and intentionality. For an adolescent, the body holds meaning and application to social relationships, self-esteem, wellbeing, and identity. For an adolescent with cancer, this is magnified as a body

with cancer refracts new understanding of one's body with every physical change and development brought on by adolescence and disease.

An adolescent diagnosed with cancer is informed of the physical impact of treatment on their body. They are aware of nausea and how to manage it. They are knowledgeable about surgical interventions and can speak about the potential resulting physical limitations. They can speak about their perception of the benefits of radiation and the lack of immediate physical side-effects. It is, however, the more insidious impacts of treatment that also brings forth emotional distress and compromise wellbeing: hair loss, muscle atrophy, skin colour changes, skin texture changes, eyebrows falling out, eyelashes falling out, stretch marks... and more. Each of these is a site of deep meaning for an adolescent and a marker of loss and change.

Yet, even with all of these markers of change, the underlying assumption held is that treatment will end, some time will pass, and these physical changes, these marks and scars of treatment, will recede and they will feel more themselves in their body. There is the held belief that their body will feel similar to how it felt prior to their cancer diagnosis. The ending of treatment though is often a beginning to living within a different body—a body that has been changed from cancer.

One of the adolescents who participated in this study, was very gaunt and frail. The side effects of his cancer treatment resulted in significant physical changes that were noticeably obvious—a pale pallor, slow and unsteady gait requiring a cane, hair loss, and a frail body. His physical presence seemed to set him apart from others in the setting within which we met: he appeared “othered” by his illness as though apart from others his age. Frank (1991) discussed those who have survived cancer as belonging to a “remission” society. He wrote that members of this society are those who have finished treatment for a disease but could never be considered

cured. They live with the markings of a diagnosis and treatment as invisible and visible scars that mark this experience and themselves. Members of this remission society live with the worries and markings of their disease. Frank argued that a shaping influence on this society is living with the threat of the future status of disease -and living in the shadow of that threat.

Frank's (1991) description of an enduring community that is marked by cancer spoke to what I was noticing regarding the adolescents I interviewed for this study and how they understood their bodies following the completion of treatment. As a caveat to Frank's assertion above, I began to wonder if the shadow is less about death and the return of cancer for adolescents but instead, the shadow is their physical sense of themselves before their diagnosis and how that might play out in their body with cancer.

When thinking about and planning this dissertation research, I was immersed in various ways of considering the posttreatment experiences of adolescents. My stance in this dissertation planning reflected my stance in clinical practice: attention to the emotional and psychosocial wellbeing of adolescents after they had completed treatment for cancer. What I had not considered was the role of the body within this context and how the meaning of the body might be at play within the posttreatment experiences of this group of young people.

The body as a site of meaning, although so connected to the experience of illness, was surprisingly not something that had elicited extensive attention from me clinically. Within the narratives of the adolescents in this study, it struck me that the body was a dominant place of meaning for them- the body of a healthy adolescent, the body as a treatment site, the body marked by illness. The meaning for adolescents of inhabiting bodies treated for cancer is not well understood. The interpretations I offer below are my attempts to understand the lived experiences of adolescents in bodies marked by cancer. I have used quotes not to offer evidence, but to offer

a new thread of understanding the phenomenological ideas I discuss. These quotes are not meant as representation but to further contextualize my offered interpretations.

### **The Body as Hermeneutical**

The bodies of adolescents have continued to inform social understanding of adolescents: the development of their bodies, their use of their bodies, and their perception of their bodies (Lerner & Steinberg, 2004). The bodies of adolescents diagnosed with cancer as a site for research inquiry has included both a psychosocial and biomedical focus. Within the realm of posttreatment, psychosocial research has investigated adolescents' perception of their bodies after cancer as manifested through research on body image and self-esteem (Larouche & Chin-Peuckert, 2006; Lee et al, 2012). Biomedical research has focused quite literally on adolescents' bodies diagnosed with cancer (Bleyer et al., 2008) and their bodies after the ending of treatment (Robison & Hudson, 2014). Listening to the adolescents who participated in this study, I have come to understand the body as hermeneutical and our engagement with our bodies as inherently hermeneutical. The body is a site of meaning and a particular to be interpreted in its context. I offer here that the body also constitutes a hermeneutical situation (Gadamer, 1960/2004) as it holds embedded knowledge that is often unexamined and assumed. Bodies come to be naturally understood in the horizon of their history: living in a healthy body in the past informs one's present living in the body.

Within the context of trauma, van der Kolk (2015) offers a similar perspective of the body as a carrier of meaning. He has proposed a robust relationship between mind and body where they are closely intertwined. In trauma, he argues the body remembers traumatic experiences and memories. Although trauma disconnects our mind and body, both the body and mind experience and hold traumatic memories and experiences. Kearney (2020) writes about the

“carnal imprint” and how the body, in his article the skin, carries emotions and suffering. Experience is located in the body and requires acknowledgement of “...the reality of your body, in all its visceral dimensions” (van der Kolk, 2015, p. 38).

Gadamer (1996) described health as a seamless practical competence that entails a forgetfulness as one disappears into the flow of everyday life. He uses the term “enigma of health” in reference to the health of the body’s transparency and hiddenness: it is an embodied equilibrium that remains “constantly concealed to us” (p.112). Health is not recognized until poor health is experienced. In times of illness, the body comes into view, or clearer into view. In this way, the health of the body is *aletheia*: as the ill body comes into view, the healthy body becomes obscured. A diagnosis of illness, then, can change understandings and self-representations of our bodies. It can challenge assumptions about our bodies and what it means to live in our body. Moules et al. (2017) discuss adolescents’ perceptions of their bodies after cancer treatment. Cancer was perceived as leaving markings that remained after cancer ended. These markings marked their self-perception and refracted how they saw their bodies. After treatment ended, as these markings came into view, the view of their healthy bodies receded.

The following are three interpretive archetypes of the body as experienced by adolescents diagnosed with cancer and how they may experience their bodies following the completion of treatment.

### **The Body as Patient**

Many adolescents found it difficult recalling specific details of their diagnosis in advance of the wave of treatment and treatment-related interventions. Most adolescents in this study could not recall being told about the diagnosis or other details about their initial days in hospital. When they did recall details, they almost always involved the body: their body feeling different

or about their observed physical changes of their body. Within the context of the onset of treatment, many remembered the impact on their bodies after diagnosis

*... because like my body just got injected with a whole bunch of poison- like liquids, and it doesn't know what to do. So it's just like attacking everything. And I remember being like having a fever shaking, like not being able to control the shaking, but feeling extremely warm like it was, it was not a good time. The diagnosis was really hard”.*

The body, from the outset of treatment, started to become a new site of meaning.

### **The Appearance of Cancer Patient**

For many of the adolescents involved in this study, cancer was a sudden appearance in their lives. To them, it happened without warning, without advance notice. It just startlingly and impressively appeared. Adolescents discussed the close proximity between their diagnosis and the onset of treatment. They described the lack of acute symptoms, or other prior indicators, informing them that something was wrong in their bodies. Many adolescents interviewed did not suspect anything was wrong with their bodies until just prior to learning of their cancer diagnosis.

In this way, adolescents were “thrown” into the world of cancer. Heidegger (1927/2010) wrote that we are thrown into the world: a world of rich, symbolic, and situated meanings. As babies, this thrownness lands us in a web of situated context that we begin to interpret to understand. As this contextual web precedes us, we interpret these established words and meanings to understand the world of which we have become part. In Gadamer’s hermeneutics, the world is interpretable and humans are self-interpreting through the language and history that they become situated within (Moules et al., 2015). Gadamer (1960/2004) wrote we exist in a “...mode of being of historicity” (p. 262). History is the prelude to understanding and we take up

the traditions that we are thrown into. After a diagnosis of cancer, adolescents take up the history of cancer. This history contains situated meanings that adolescents integrate with their current horizon of being an adolescent: they become adolescent cancer patients.

The word “appear” as referenced above is a further portal to understanding adolescents’ experiences with their bodies as cancer patients. The etymological origin of appear is from the late 13<sup>th</sup> century old French word *aparoir* which means “come into view” (Online Etymology Dictionary, 2021). Following a cancer diagnosis and within the beginning phase of treatment, a cancer patient comes into view. Although cancer lurks at the edges of one’s body following a diagnosis, it still rests within these edges. A body of a cancer patient eventually comes into clearer view as treatment progresses. The loss of hair, the pale skin, the weight loss, the weight gain, the slower pace of movement—all of these are markers of a body in cancer treatment. These bodily changes induced from a cancer diagnosis challenged the prejudices of the body held by adolescents: prejudices of a healthy body. Prejudices are guides, judgements, that Gadamer (1960/2004) argued we inherit from history. They fit us until they do not. They are replaced by new understanding in situated contexts as we create new interpretations of our experience.

Adolescents hold prejudices of their body. Their prejudices involve understandings of their body involving health, strength, and activity. These prejudices were replaced by the physical markers of cancer their bodies were taking on following a cancer diagnosis. Many adolescents that I spoke to seemed to define themselves through their body prior to their diagnosis: they defined themselves physically. They spoke about lives before cancer that were filled with physical movement: school, sports, friends, activities. To them, these were the

markers of a life before cancer. They described themselves as having “typical” lives prior to a cancer diagnosis:

*Very active, a lot of sports, a lot of friends. Doing something every day, like all day, every day. Yeah, that’s basically what I was doing.; It was a normal teenager life until I started getting the headaches and the nausea and all that. I was able to play soccer, hang out with friends, play all the sports that I loved, and participate in school.*

Heidegger (2010) described appearance phenomenologically as something as “announcing of itself through something that shows itself” (p. 28). What he means by this is that the appearance of something does not indicate itself, but rather is indicative of something else that announces itself but does not show itself. Within cancer, the appearance of physical symptoms attributed to cancer treatment announces the presence of a life-threatening disease. Disease does not appear itself but is shown through the physical changes associated with disease. To adolescents, these physical changes announced the appearance of cancer and themselves as cancer patients. Prior to cancer, the health of the body was often taken for granted by adolescents. Although attention to indicators of health in the body are likely more apparent for older people diagnosed with cancer, health of the body for most adolescents had not been offered distinct consideration in advance by most adolescents of their cancer diagnosis.

Prior to cancer, many adolescents interviewed had no experience with a serious illness and its disease and treatment-related impacts on the body. Changes in the body seemed to make cancer more visible to them. I suggest that these changes made their cancer diagnosis feel more real. These changes in the body acted to bring the abstract nature of their disease into concrete awareness and personal engagement. The body was changing following their cancer diagnosis and within the experience of having cancer and being treated for cancer. The accommodation of

these changes and the meaning of the changes to adolescents was confronting as they adjusted to these changes within the context of a disease. They began to feel different in their bodies and they experienced their bodies.

*For me, I just found the treatment was hard sometimes because I felt really sick so that was hard to get used to. I just remember wanting the feeling sickness in my body to end, then, thankfully I would just kind of fall asleep or just kind of sleep through the days. The impact to my body was really hard- my body was shrinking away which was really hard. And for me that, was even harder than feeling sick from the treatment- I often lay there looking at my body and seeing my muscles shrink away and seeing no muscle tone on my legs, my arms... and that was really hard. Like I really defined myself as a physical sort of active person and it was really hard to see these changes in my body. I didn't know if my body would come back and how long before it did. I felt really alone actually at that time and that like no-one felt the way I did. But like not just on the physical side effects from cancer, like I kind of got used to that. But it was more what I just talked about- the way my body was physically changing from the cancer and I really didn't like that. I felt really helpless and my body became really hard to look at.*

*And so, me I had really long hair at the time, like past my butt kind of long hair; been growing it since like grade four. And so my first ever question was like am I going to lose my hair? And then I just like I lost it. Like when my nurse clinician said yes. And like, I was like, I just cried over that, like, that was my biggest thing... am I gonna lose my hair. Losing my hair was harder than I thought it was going to be. I had had long hair for so long, like, seven, eight years. So it was really it was really strange to like, have a lot of*

*that weight off your head quite literally. I really felt like losing my hair was changing who I am and who I thought I was. I worried about what effect this might have on me- like how would I feel without my hair? I began to feel different- I began to feel sick.*

Approaching the end of treatment, the unknown has been brought into increasing contact with the known as adolescents are confronted by both their cancer body and non-cancer body. Adolescents talked about both changes in their body and constancy about their body. This intersection of the familiar and not familiar continues to move adolescents in and out of the hermeneutic circle. This back and forth, this ebb and flow, offers an image of how adolescents move in and out of the specific and whole context of their cancer experience and use their body as a thread weaving through the circle. The ending of treatment from the perspective of their body, brought adolescents a sense of increased expectation and comparison to “normal” bodies and to their normal bodies specifically. However, they still held the indicators of being a cancer patient: *so when I got my eyebrows back- that was huge. Like I could kind of pass for a kid who didn't have cancer- I could have just been a kid that shaved my head.*

### **The Body as Not Typical**

*Well, before cancer I was this typical guy before, really active, like a really physically fit and then my appearance was really different which was really, really hard for me. There were days where I just thought about it too much – maybe trying to do something, like go up the stairs, and I couldn't without holding on to the wall or something. I remember when I first got surgery, maybe a little bit after, I tried playing checkers with my grandfather and I got really, really mad, because I just couldn't pick up the checker pieces. It was just me ... I was getting upset over things. A difficult day would be where I just thought too much about it and it just made me really, really upset. I'd usually just tell*

*my mom, 'Mom, I'm not having a good day.' And we would sit down and I would usually cry for a bit, but it's always nice to get that out. Or I should be able to walk up the stairs like I said without walking into the wall, but I couldn't. Just remembering that you do struggle with some things and you do have to work a little harder with some things. Since like being told that you've got cancer all over again ... like I never – like at the beginning, when they first told me, I didn't really think anything about it and tried to shut it down then, but a difficult day would be like when you just can't shut it down anymore. You have to think about it and realize what it means.*

*You look different. You don't look like a normal person. I don't want to use the word freak, because that's not the right word, but you just catch people's eyes and have all those eyes staring you ... it's kind of intimidating and makes you feel weird.*

*I've been like super stiff lately. It's just hard to get used to being who you were before you had cancer and trying to get to that person who you were before you had cancer, because you're a totally different person I feel. Just like your body has changed, I mean like joints and everything ... you've been in the beds for so long and no muscles anymore. You have to build it all back up. It's just like you're a totally different person. It feels like to just come out of the hospital and ... I don't know. Yeah, just a totally different person in your body*

Many adolescents discussed significant changes to their bodies and the necessary contrast of their bodies before and after their diagnosis. I offer that for many, these changes were not attended to from adolescents until the end of treatment. The body as not typical was perhaps

understood as typical within the context of treatment. When treatment ended, the atypical aspects of the changed body from cancer, received their greater attention and awareness.

Throughout treatment, and following the completion of treatment, the body can feel foreign and unknown: living within this body can feel like adapting to a stranger's body. To some adolescents interviewed, the body barely felt recognizable. Adolescents talked about feeling like the same person but not recognizing their body. Leder (1990) discussed that the coming to awareness of the body in illness can be alienating, confronting, and incommunicable to someone who has not shared that bodily experience. He uses the term "disappearance" to refer to this phenomenological experience. The word "typical" was used by many adolescents in reference to a description of their bodies. Typical appeared to be a consistent point of meaning in which to locate themselves prior to their diagnosis of cancer. One definition of typical is the "combining or exhibiting the essential characteristics of a group" (Merriam Webster Online, 2021). One belongs to one group or another and these groups have unifying qualities. In this sense, I am interpreting group to mean not a social group per se but rather, the experience of embodiment as a healthy body or sick body.

Gadamer argued that understanding can not be isolated from history and tradition (1960/2004). In this spirit, I offer two different ways the body is viewed philosophically and that inform the body as a tradition of understanding for adolescents diagnosed with cancer. The perception of the ill body as not typical aligns with a naturalistic tradition of knowledge and a body-as-object orientation (Gadamer, 1996). A naturalistic conception of the body lends itself to the perception of the body as the "what" of the body. The German term "Körper", the corporeal body, supports the idea of body as a physical structure (Gadamer, 1996). A corporeal body is a reference to a causally determined substance and "readily susceptible to objectification and

processes of measurement” (Gadamer, 1996, p.134). The body becomes viewed as an object of measurement. A body perceived in this way is structural. It is devoid of context and the holistic perception of the body is marked by an anatomical image.

Biomedical models have traditionally regarded illness as a deviation from the normalcy of being well. Throughout the past century, the concept of health was defined and largely accepted in terms of the lack of disease or observable illness symptoms, signs or problems experienced (Boruchovitch & Mednick, 2002). The body has traditionally been perceived as an object within health care practice. Gadamer wrote that modern science and the objectifying framework inherent in the practice of medicine has created a “violent estrangement” from ourselves as situated and embodied beings (Gadamer, 1996, p. 70). The body has become a site of inquiry and has been experienced as such in medical practice. This is supported by the practice of assessing health by evaluating objective and observable disease indicators. Within clinical health care practice, there exists an approach of Cartesian dualism. Descartes argued that the mental and physical components of self were distinct from each other: one was not needed by the other (Thibaut, 2018). This separation of the mind and body, this conceptualization of the body being independent from other aspects of the self, continues to remain at play within the clinical care of adolescents diagnosed with cancer. This implicit dichotomy of illness and health neglects the wholistic complexity of wellness. The assessment of adolescent wellbeing in oncology practice is often separated into parts: psychological distress, physical rehabilitation, and quality of life domains identified as indicative of psychosocial wellbeing. These necessitate referrals to physiotherapy, social work, psychology. The multidisciplinary practice of these professions further separates the wholistic experiences of patients. These parts are considered and examined in distance with little acknowledgement of the holism that binds these parts.

An alternate orientation of the body is the perspective as body-as-subject. According to Heidegger, “man’s substance” is not spirit as a synthesis of mind and body; it is rather existence” (Heidegger, 2010, p.117). The body is not seen as a corporeal body but rather, what Gadamer referred to as a lived body in life (*Leib*). In this philosophical tradition, the body can not be understood as separate from the life lived by the body. *Leib* is a reference to the lived-body, to one’s own bodily experiences, feelings, and perceptions. The lived-body, or the body of being, is not something we have but rather, who we are as an embodied way of being: we do not have a body, rather we are bodily (Heidegger, 2010). To Merleau-Ponty (1962), one’s body was also synonymous with existence: we do not have bodies, we are bodies. According to Merleau-Ponty (1962), we know and understand the world through our bodies. The body is the vehicle for being in the world and structures our relationship to the world. In this perspective, the body can not be understood as separate from the world it engages and participates in as embodiment occupies a fundamental role in structuring daily life: we come to understand the world through our body.

### **Dialectic of Bodily Experience**

I offer here that the body as corporeal and the body as *Lieb* reflect the dialectic experienced by adolescents as they experience both their body-as object and their body-as-subject following a diagnosis of cancer. Prior to their diagnosis, they experience the body as *Lieb*: a lived body that was seamlessly situated in the world. They are able to navigate the world in their lived body as the contextual world is familiar. The body did not call their attention. However, a cancer diagnosis and the resulting physical impact, does call attention to the body. For adolescents, their body becomes corporeal to them: it shifts their attention to their body in a different way. The body becomes a site for analysis and separation as physical symptoms and bodily changes requires attention to the body as a physical structure. This dialectic is also at play

systemically following a diagnosis of cancer. The adolescent's body suddenly becomes perceived as corporeal within the context of the cancer system. The body is the focus of attention and the meaning of living within the body, the *Lieb*, is less attended to clinically. Gadamer (1996) discusses this as the challenge that confronts medicine: coming to an understanding of the body as a lived experience of being in the world through the application of general principles of science to the particular situation of the patient.

### **The Body as Disruption**

*Since like being told that I had cancer ... like I never – like at the beginning, when they first told me, I didn't really think anything about it and tried to shut it down then, but a difficult day would be like when you just can't shut it down anymore. You have to think about it and realize what it means. (What does it mean to you?) It means that I am a different person now. I am trying to figure out how I can still be me in different parts of my life but by body, and sometimes, um, my memory doesn't work the same anymore. It means I am trying to figure out how to live life the way I want to with my body, my physical limitations. And I think I might always have to do that.*

*That has been really tough actually. I was a very active person and I excelled in rugby and all of a sudden I feel like a senior citizen- like my body is weary, and my bones are brittle, and I don't feel like I know my body at all anymore. I don't know what to expect from my body or even what to hope for with body. And I think that's the hard part about this is that I am trying to emotionally recover from treatment but my body is going backward- it doesn't feel like my body anymore and I don't know what the future with my body will feel like. My body makes me nervous, and scared and just really*

*angry and sad sometimes. (Is crying).... When I entered treatment, I felt like after, it was just going to be, like you go back to normal, like how things were before. Like, you can go do sports, you can, you can work a part time, full time, whatever job, you can go to college and not worry about, like the side effects or whatever, like things go back to normal, but it just, it's just not normal. And I guess after something like cancer, things don't go back to normal. Like, I still, like would still be engaging different with my body and thinking about my body after treatment. Like, I thought life would be different and that I thought it would be back to a pre-treatment world.*

I was struck by this adolescent's narrative and the emotional intensity surrounding her sharing of it. Her use of the word "backward" within the forward trajectory of cancer is a curious juxtaposition: moving forward but feeling backward. George (2020) discussed the concept of hermeneutic displacement within the context of understanding. To understand he argued, one must be open to being displaced in our current understanding. "Whatever it is, the experience of displacement is a confrontation with alterity, the other or exteriority" (p. 48). He highlighted Gadamer's belief that "hermeneutical experience takes shape "in the polarity of familiarity and strangeness" between a matter or "object" under our hermeneutical consideration... the true locus of hermeneutics is this in-between" (p. 49). This in-between, this displacement, I offer also extends to our understanding of our bodies and that a diagnosis of cancer displaces adolescents within their bodies and their understanding of their bodies.

Although the body changes were often accommodated to during treatment, the implications of living in a body with these more permanent cancer or treatment-related changes seemed to be considered in a different way following the end of treatment. Within their descriptions of posttreatment changes and losses, adolescents irrevocably and consistently

contrasted this with descriptions of their bodies before their cancer diagnosis and treatment: to them one is linked to the other. They could not speak about posttreatment without the telling of who they were before their cancer diagnosis. This was consistent and I adapted my interviewing practice to accommodate this observation and I began to ask them about their bodies. There was a chronology of their body that they conceptualized and spoke to: to understand their experiences with cancer, it was necessary to invoke this biography of their body. This chronology structured the trajectory of their body as they came to understand it.

I began to understand that adolescents held assumptions about their body after treatment ended. There was an assumption of a healthy body after treatment: the cancer would be gone and the body would return as it was. There was also an assumption that the body would feel as it had before their diagnosis and they could use their body in the same way they had before their cancer diagnosis. The experience of cancer challenged their taken-for-granted assumptions about their bodies. Adolescents treated for cancer and that live with resulting physical impact, experienced ruptures in the “taken for granted assumptions and behaviours” that structured their daily lives (Bury, 1982, p. 169). Their bodies were experienced as new bodies for some and bodies they had not lived in fully prior to the end of treatment.

*I wouldn't say my body feels like it did or how I want it to feel but I am feeling more comfortable in my body- like I know how it feels and what to expect with it. I don't feel strong in my body but I am trying to get used to that. I still don't really know my body- I mean, what it can do, what I need to do to feel strong again but I think it's getting better. I just try to keep my body as healthy as I can. It was really strange seeing your body fade away to nothing and then if you go back and try and work out again, doing the same kind of stuff you're doing before and you can't. Like you get so tired – like imagine before I*

*could ... you could run for kilometers and kilometers on end without having issue, and now like you run for a couple for minutes and you're done. You're tired out completely.*

*You kind of go back into it expecting you're going to be fine again, but your body is so weak and so fatigued after like the constant fighting the chemo and stuff and cancer and stuff. You have to ease back. You really have to start back from square one. I just feel really different in my body but it's coming back. It was the physical thing that got me down even when I was trying to stay positive. I just looked at myself in the mirror and I'm like, "Oh you look gross, you look weak" kind of thing and then all of the sudden in the back of my head, I'm also thinking like, "Okay, you didn't really have an option. You didn't do this to yourself. It just kind of happened from the chemo" ... there is still work involved to be a healthy kid again.*

Changes in the body, and experiencing the body as altered, can be an experience of loss and mourning the body before cancer. Many adolescents lived within changed bodies after treatment ended: cognitive changes from brain tumours, a lost limb from a bone tumour, steroid-induced avascular necrosis from bone marrow transplant. The bodies of these adolescents are marked by their cancer diagnosis and will be permanently altered. Many adolescents were let down by their body and grieved the body that they had prior to their diagnosis. There was a strong sense of disappointment in their bodies as some described their experiences. This disappointment in the ways the body acted, and the way body looked when treatment ended. There was a lack of competence in this body—although the body could let them down. The vulnerability of the body, and this perceived fragility of the body, was a stark contrast to the descriptors of strength and wellbeing that adolescents felt about their bodies prior to a cancer

diagnosis. The everyday experiences of navigating this new body, this altered body, were difficult.

Biographical disruption is a concept in medical sociology that has been utilized to explore the structural context of diverse illness experiences. This term conceptualizes illness as a disruptive event (Bury, 1982). This concept was originally applied in the context of the onset of, and living with, chronic illness but it has also been applied in the context of cancer as an acute illness (Hubbard et al., 2010). According to Bury, there are three aspects of disruption in the unfolding of a chronic illness: 1) “the disruption of taken for-granted assumptions and behaviours”. These assumptions and behaviors are located within the body and bodily states 2) “fundamental re-thinking of the person’s biography and self-concept” and 3) a response to disruption involving the mobilisation of resources, in facing an altered situation.

I offer here that the experience of disruption is at play within the context of illness. Etymologically, the term disrupt stems from “break or burst asunder, separate forcibly” (Online Etymology Dictionary, 2021). For some adolescents, they are separated forcibly from their bodies before their cancer diagnosis. Disruption involves some change or deterioration of the capabilities of the body and one’s embodied orientation towards the world: a shift in their physical engagement with the world around them. The body as a site of disruption suggests that the explanatory frameworks used for understanding one’s body in daily life are also disrupted. For adolescents, this might create impact in contexts of relationships, school, employment, and physical activities which we know from research that these are areas compromised by an adolescent’s cancer diagnosis and treatment (D’Agostino et al., 2011; Zebrack, 2011). Grinyer (2007) argues that adolescents do experience a biographical disruption from cancer and that due to their age and the developmental transitions they are experiencing, biographical disruption may

be exacerbated. When people are unable to enact familiar routines and activities, attention to bodily states not usually brought into consciousness are brought into view. Adolescents are displaced within their bodies concurrently with the broad expectation of their life feeling more familiar and less strange following the end of cancer treatment.

### **Posttreatment as Embodied**

Throughout this chapter I have suggested that both cancer and treatment is embodied for adolescents: both of these experiences bring renewed attention to the body and living within a body. The above interpretations suggest that posttreatment is also embodied and perhaps experienced as more embodied than other times in the cancer trajectory. During posttreatment, the body in its new form is met and requires adaptation within its embeddedness in the world. The body is reclaimed after the ending of cancer treatment and for many adolescents, their experiences in, and of their body, constituted their adaptation to posttreatment. The body was a focus for them as they discussed both the challenges, complexity, and sometimes ease, of transitioning to a posttreatment period of time. I offer that their bodies impacted their subjective wellbeing and that the body was inseparable from living life after cancer treatment had ended.

### **Final Thoughts**

The body is hermeneutical: it is a context to be interpreted and meaning to be created. My intention in this chapter was to offer interpretive understanding to the meaning adolescents make of their bodies within the experience of cancer and during posttreatment. I used the philosophical ideas of body as-being to explore the meaning of living within bodies diagnosed with and treated for cancer. I have outlined some ideas of the body and then used these as a context to explore adolescents' experiences of the body: the body as patient, the body as not typical, and the body as disruption. The posttreatment experiences of adolescents are informed by adolescents'

experiences within their bodies during cancer treatment. Understanding the body as constitutive of being (Heidegger, 1927/2010) nudges greater awareness towards expanding the bifurcation of mind and body that often is utilized within clinical practice with adolescents. Within medical practice, the body is instrumentalized (Gadamer, 1996)—both biomedically and psychosocially. There has been a narrow focus of exploration of the body in adolescent oncology yet the body holds much meaning for adolescents and the meaning of living within different bodies, warrants deeper understanding.

## Chapter Six: Posttreatment as a Liminal Space

### Introduction

This chapter explores adolescents' embeddedness within a posttreatment period of time. Posttreatment as understood by many of the adolescents interviewed for this study, was experienced by many as a time of disorientation: a time of uncertainty and suspended expectation. Much like adapting to their bodies after treatment ended, adjusting to life after cancer treatment had ended also required adaptation. Within this exploration, I offer conceptual lenses of displacement and liminality to orient this chapter and I pick up threads within each of these broad conceptual categories to explore and deepen consideration of adolescents' living within the time and space of posttreatment.

### Disorientation

The ending of cancer treatment is perceived as a milestone in a cancer patient's "journey". It is perceived as an ending of a defined trajectory of treatment. Ending treatment is generally believed to be a time of return to one's life prior to a cancer diagnosis and an invitation for more life to be experienced. Although medical late effects are widely acknowledged for adolescents and young adults treated for cancer (Mulrooney et al., 2008; Soliman & Agresta, 2008; Spathis et al., 2017; Tai et al., 2012), the ending of cancer treatment is believed to be a happy time and a gateway beyond the immediate challenges and suffering of cancer treatment.

*I think I just knew that I had a lot of work and time ahead of me but I didn't really know what that would be like- like what to do to feel more myself or to feel normal or whatever. It was just kind of this weird time when I had been through something big and something that most people haven't been through. And then suddenly I was home and I was like "so*

*what now?" So it was hard because I just didn't know what to do or how to get things back on track.*

Many adolescents in this study also did not know which way to go once treatment ended. Following the completion of cancer treatment, there is not a recognized protocol or established path or framework to guide the way forward. There were no markers, no indicators of expectations or movement, that they can orient towards. This was different than the experience at a cancer diagnosis: they were given a treatment plan to identify and mark the complex path of treatment that children and adolescents (and their families) embark upon. Throughout treatment, this road map guides a child/adolescent and their families' way. Once treatment has ended, there is not a map to guide their path.

For many adolescents in this study, experiencing posttreatment was disorienting and confusing. There was an experienced uncertainty to their experience. There was an added element of confusion to this disorientation as many adolescents did not expect to feel this way. They looked forward to the end of treatment and held it in sight often immediately following their cancer diagnosis. To them, the ending seemed to be a goal-post, a finish-line of sorts, and a signal for their life to return to ways it had prior to their diagnosis. However, many adolescents experienced the initial time of posttreatment as under-whelming: it did not live up to the celebration and relief that they were expecting to feel.

*I don't know, I thought posttreatment, I thought it was going to feel like, like a euphoria, like, kind of like a heavenly sort of thing.*

*Actually, it (treatment) was better in some ways and I was like "thank god that's over." I felt like I was fighting for a long time. It was just a huge relief when I found it was*

*done. And I was just like, “I’m ready”. But it was kind of anticlimactic. Maybe a bit because I’d been like, going so hard at it and then all of a sudden, that stopped. So it was kind of hard afterwards, just kind of to like, you know, be normal, I guess.*

### **Posttreatment as Displacement**

#### **Displacement**

*I just really couldn’t make sense of the fact that I had cancer. I really didn’t. Your life goes on unfortunately, but not in the same way that it was. There’s nothing you can do. You just kind of have to let it happen. I mean that’s pretty much it. I mean you realize that you had cancer, but you can’t really relate to it. It’s just something that you had and you had to deal with. You can’t really relate to it at all.*

*I just don’t know how to get back to my life.*

*I think I expected to feel sick in hospital when I was getting my treatments. But I still feel sick and my treatments have stopped- I don’t feel the same in my body. I feel sick a lot which is hard to understand- I just don’t feel myself and how I used to feel in my body before getting cancer. I thought I would feel better after my treatments stopped but I don’t and that makes me sad. I wonder when I might feel myself again.*

I suggest that the time of posttreatment after a cancer diagnosis is not just disorienting but it is displacing: it is a time of displacement. To understand a different vantage point of the word “displacement”, a return to its historical meaning is helpful. The etymological origin of displacement from the 1550s is “to remove to a different place, put out of the usual place” (Online Etymology Dictionary, 2021). Displacement then is a shift, an experience of sudden ill-fit—it’s an experience of contested change.

As I suggest throughout this chapter, the posttreatment experiences for many adolescents involves a removal to a different place. Posttreatment is a removal from cancer treatment: adolescents are put out of the usual place of cancer that they have come to expect and feel as familiar. During posttreatment, they are removed from the defined experience of “cancer” and are removed to an unknown place of “after cancer”. As the preceding narratives offer, many adolescents felt the unknown of this “after cancer” period of time: they did not know what to expect or how they should feel. They are displaced between treatment and the ending of treatment. This removal from cancer is a different way to consider posttreatment. Prominent and popular narratives around cancer diagnosis attend to the removal from one’s life at the time of diagnosis, but one’s removal from cancer within the context of posttreatment has not been articulated. George (2020) suggested that displacement is definitive of hermeneutical experience. He argued that the capacity for displacement should be recognized as essential to the experience of understanding. Displacement he suggests can feel like a disruption as one confronts what the unknown offers. For many adolescents in this study, posttreatment felt like a disruption: a disruption in their situated experience within cancer.

*Yeah, I began noticing that cancer became a huge part of my life and it was difficult to think of my life in ways different from cancer. It was such a hard part of my life and now it’s over and I’m moving on to the next part of my life and it’s hard to distinguish that ... when to start this and when to end this, and I like I never thought anything would be over or that my cancer journey would be done and finished. I always thought that I would be forever marked by this ... like I would forever be the person that, okay, he’s made it through cancer this one time, now two years later, five years later, he gets it again – what’s the next thing that’s going to show up?*

Gadamer (1996) addressed a similar stance of displacement within his writing of equilibrium. He argued that illness disrupts an equilibrium of a person. Equilibrium here does not merely refer to a physical homeostasis, but rather to a broader balance within a person and their embeddedness within one's life. Illness disrupts this balance and creates disruptions to one's life. Health therefore is not a static experience but oscillates between maintenance, disruptions, and reestablishments. Restoring equilibrium within a person, then is not simply a restoration of the pre-illness condition, but a restoration of the disturbance of the whole person in this new life. In Gadamer's (1996) view, the sick person falls out of things and has fallen out of their normal place in life. After illness then, people desire a return to an equilibrium and a restoration of the preceding disruptions.

### **Cancer Survivorship**

As I discussed within the preceding literature review, the time of more immediate posttreatment is not often articulated, or un-specified, outside of the longer and broader time of discourses of cancer survivorship. I offer that some of the displacement of posttreatment experienced by adolescents can be understood by the epistemological history that has framed posttreatment and cancer survivorship both systemically and within public discourse. I suggest that these perspectives have informed how adolescents approach and consider this period of time.

Although Gadamer's (1996) claim above that illness constitutes a disruption of the whole and extensive psychosocial research has suggested that the diagnosis of cancer has holistic impact for adolescents (D'Agostino et al., 2011; Jones et al., 2020), the diagnosis and treatment experience are separated, and I suggest experienced, as parts following a diagnosis of cancer. Tumours are staged, chemo treatment is delivered in phases, and patients are oriented towards the markers of diagnosis, treatment, and maintenance. The experience of cancer is therefore

implicitly compartmentalized as patients become oriented to seeing their cancer diagnosis and treatment as different parts. For people finishing cancer treatment, there is likely the expectation that posttreatment would feel differently than how treatment felt as posttreatment was a different “part” of the cancer experience.

The conceptualization of cancer survivorship discourse often contains an implicit binary: on treatment and off treatment. Anecdotally in oncology practice, there is the assumption of a seamless transition between these two parts of the cancer experience: patients transition well from on treatment to off treatment. The word “survivor” comes from the Latin word *supervivere* which means “live beyond, live longer than” (Online Etymology Dictionary, 2021). In these etymological origins, there is the suggestion of a demarcation between living with cancer in the context of diagnosis and treatment and living beyond cancer following the end of active treatment. Traditionally, they are understood to comprise different experiences. “Survivorship” is a widely used concept applied following the completion of cancer treatment. A working definition of cancer survivorship is “.. individuals with cancer who have completed primary treatment for cancer” (Feuerstein, 2002, p.6). This author recognizes that the term survivorship also includes people who continue to receive maintenance treatment but who have “completed primary treatment or the major aspects of treatment and either desire or need to “get on with their lives” (Feuerstein, 2002, p.6). Within this definition, is the understanding that survivorship is a discrete period of time and that one can put their cancer diagnosis and treatment behind them. Survivorship” is also positioned as an all-encompassing category following the cessation of active treatment and I suggest, is perceived unexamined as a homogenous category of the cancer experience.

Although the working definition of survivorship noted above is actively taken up in clinical practice realms, new definitions of what constitutes a cancer survivor have been developed over the years. Mullan (1985) challenged the binary between cure and still living with overt disease and proposed cancer survivorship as a category that includes both those who have been cured from cancer and those that are still receiving interventions to manage their disease. He suggested that “the vagaries, phases, and syndromes of survivors are far more complex than the simple idea of cure suggests” and the commonalities experienced by those living within diverse post-cancer contexts are shared more strongly than with people who hadn’t been diagnosed with cancer (Mullan, 1985). Mullan proposed stages of survival within cancer survivorship: 1) the acute stage refers to the time of diagnosis through the end of treatment, 2) the extended stage is the time of treatment and 3) the permanent stage refers to the long-term stage of survival. The Lance Armstrong Foundation developed a similar model describing the chapters of survivorship that accompany someone’s movement through cancer survivorship (Naus et al., 2009). These include: living with cancer as the period of diagnosis and treatment, living with cancer as the time from ending treatment to five years post-diagnosis, and living beyond cancer which includes five years or more following the cancer diagnosis. Although each of these frameworks widened the context of survivorship, neither recognized posttreatment as a potentially unique or vulnerable time within this trajectory. As attention to the needs of adolescents and young adults who have been treated for cancer continue to grow, there is greater planning and articulation of models of survivorship care for this group of young people (Canadian Partnership Against Cancer, 2019; Linendoll et al., 2020). Although the unique needs of AYAs off cancer treatment are increasingly being recognized and responded to, attention to a

more immediate posttreatment time has been neglected. Posttreatment remains an unknown and invisible period of time for people living with a posttreatment space.

Finally, messages involving cancer survivorship have been actively taken up within the public realm. The breast cancer community has widely advocated “survive and thrive” following the ending of treatment, references to “winning the war” on cancer remain prevalent, and “cancer warrior” have all become defining tropes of cancer. A discourse analysis study of online self-representations offered by young adults who had completed treatment for cancer found that this group described themselves as empowered and motivated to make cancer a positive experience in their lives (Lewis & Weston, 2019). Within these expressions, there are messages of overcoming adversity, accomplishment, and success following the end of treatment. There is also the positioning of the cancer patient who had finished treatment as capable of tackling bravely and confidently this new posttreatment life ahead of them.

### **Temporal Disruption**

*As soon as I was diagnosed with cancer, I was just like “ok- let’s get this done”. I just kept thinking to the future and when I would be through this...when cancer would be done and I could get my life back.*

*It’s just been really hard because I thought that life would feel like it was moving forward after treatment- like this new chapter of my life would be defined right now. But instead, I feel caught in a book with many chapters and I really don’t know in which chapter I am supposed to be in. Life is moving so slow for me right now and I don’t like it.*

“*Future, get my life back, moving forward...*” words taken from these narratives were words found integrated with many of the narratives offered by adolescents in this study. For many adolescents in this study, a diagnosis of cancer seemed to create heightened temporal awareness and specifically, future temporality. Both directly from their narratives and indirectly from my interpretations listening to them speak, many held the belief that the future was not as they had imagined. They were not feeling happy, they were not feeling healthy, and they were not feeling well integrated into their life. Posttreatment as the future that they had been imagining throughout treatment was not what they expected.

Temporality is the subjective progression through time (Dawson, 2014). Temporality is not time per se, but one’s experience moving through time. Temporality is traditionally the linear progression of past, present, and future but Heidegger (1927/2010) takes up temporality ontologically. Heidegger writes that temporality is the horizon of being: the meaning of being is constituted through the movement through time. Time in this perspective is not linear time but rather a unity between past, present and future. He does not conceptualize these as separate, proximal categories but rather, dimensions that are mutually implicated in one another: the future is implicated in the past (Heidegger, 1927/2010). This temporal unity creates one’s temporal interpretation of time and therefore, one’s being through time.

Within many of the narratives offered by adolescents in this study, there was a strong future orientation when speaking about their past diagnosis and treatment experiences. Many referenced the future when discussing treatment: they kept their gaze on the future when treatment would be finished. The future seemed to act like a marker: a marker that treatment was completed and “normal” life could be returned to...*get things back on track*. Breaden (1997) proposed that during treatment, time stands still and the future is temporarily arrested. However,

for many adolescents in this study, the future was invoked immediately following their diagnosis: they seemed to orient themselves in the future almost as a goal or a motivation. For other adolescents, the future orientation became even stronger during posttreatment as they continued to look beyond this period of time as they hoped that life would be different (better) in the future. This future orientation remained strong and enduring. One adolescent I interviewed cried openly when discussing his posttreatment challenges. His posttreatment experiences included bullying and loneliness: he described emotional suffering during this time. However, he also reflected on his belief that life would feel more normal in the future and advised other adolescents to focus on the future throughout treatment and posttreatment. This was despite him not yet having had experiences where the future held greater normalcy or wellbeing for him. The future had not changed anything for him yet he had a strong belief that it would and that things would be better for him in the future. However, his continued future imagining seemed to reassure and comfort him. He maintained a strong relationship with future time and was oriented to this temporal progression through his cancer experience.

Bykvist (2013) discussed that we are often biased towards the future and that this orientation is enduring within present experiences and perceptions of pain and difficulty that we may experience or are experiencing. Developmentally, adolescents are oriented to, and develop this orientation to, the future and have a strong relationship with future-oriented time. Future goals and interests often co-occur with life-span development and specific developmental tasks of this period. Future orientation often facilitates setting goals, planning, and making commitments that guide behavior. (Nurmi, 1991). Seginer (2008) discussed how adolescents preserve future orientation when confronted by adversity and challenge. She argues that having

hope mediates adversity and challenge within future orientation and the development and maintenance of hope preserves the construction of future orientation in times of high threat.

Many adolescents in this study did maintain hope that the future of posttreatment would be different than their current treatment context. However, when posttreatment created a context of uncertainty, and the future did not feel the way they had hoped, many may have felt displaced between the present and the future. Looking forward to the future was an anchor for many adolescents throughout their treatment. However, for many, the future, “the posttreatment future”, did not feel as they expected it would feel. Within Heidegger’s (1927/2010) conceptualization of the unity of temporality, there was a displacement between the experience of the present and the future: these were separate entities experienced differently.

### **Normal - Not Normal**

Within consideration of displacement, and being displaced, there is an implicit space of “normal” invoked: somewhere that we have been displaced from. Within the experiences shared by many of the adolescents in this study, there was a dominant thread of their desire for normalcy. While in the midst of treatment, adolescents looked forward to “normal life” following the ending of cancer treatment and when cancer treatment was completed, they assumed they could easily return to their “normal life”. This return to normal did not seem to be questioned by many adolescents during their cancer treatment. A return to normal seemed to act as a guiding marker for adolescents as they moved through their cancer treatment and its completion.

*I just wanted to go back to the way it was – that’s why I did everything to kind of get my old life back.*

*I just tried to stay positive and that things will be back to normal one day...I did begin to wonder what cancer would do to me and when I would feel normal again.*

*I have been thinking about that (what normal is) but I don't really know right now. I just know that I want to feel like my life is moving forward, that it has purpose, that I have full and busy life.*

*I just wanted to get back to my normal life. I just thought I would be happy by now, have friends, want to go to school, maybe have a job. I didn't think I would be feeling so sad all the time and would be happy about what I have been through and who I am now... I just want to feel normal like that. I think I just need to stay positive and just try to get back to normal- try to do what I was doing before I got sick. I am trying not to think too much about my treatment. I try to think about things that make me happy. I think time will help me.*

When asked what a “normal” life looked like, adolescents consistently spoke about aspects of life prior to their diagnosis: attending school, spending time with friends, participating in sports and activities etc. Many adolescents spoke of the importance of normality and wanting to maintain “normal” aspects of life after treatment ends. Many seem to perceive cancer as an event- an interruption in their lives but one that would be over and reconciled following the end of treatment.

The belief that they would “return to normal” dominated the beliefs of many adolescents interviewed about their ideas of what posttreatment would be like. The desire for normalcy was also institutionalized within their health care experiences and interpersonally expressed by their

friends and families. Adolescents spoke of staff encouraging them to “get back to normal” after treatment had ended and their parents wanting them to return to a normal life prior to cancer. *My doctor basically said go back to normal. Take it easy. Don't overexert yourself, but go back to being normal and go back to your old life – try to anyways.* Within these uses of the term “normal”, there are unexamined assumptions that one can return to normal following a cancer diagnosis and treatment and also that normal can be clearly conceptualized by those returning to it.

The desire for normal surrounds the treatment and posttreatment experiences of many people diagnosed with cancer. However, I offer here that something different is at play with “normal” in the context of adolescents who have completed treatment. Exploring the term “normal” offers a new avenue of understanding this term in context and in my understanding, has become a “turning word”. Davey (2006) defined a turning word as a word that captures the indeterminate nature of language and that reveals a different meaning of a word's established usage. The term “normal” is defined as “conforming to a type, standard, or regular pattern: characterized by that which is considered usual, typical or routine” (Merriam Webster Online, 2021). Etymologically, it originates from “conforming to common standards or established order or usage, regular, usual” (Online Etymological Dictionary, 2020). Normal then is established order. Normal is routine and regular.

Throughout the narratives offered by adolescents in this study, there were repeated references to established order, routine, and regular, regarding how adolescents experienced cancer treatment. Overwhelmingly, they described treatment as an established routine and rhythm and routine. They spoke about the rhythm of treatment: the natural temporal pace of the treatment context that they fell into following their diagnosis. Following their cancer diagnosis,

they fell into a routine that was maintained throughout the duration of their treatment. Many adolescents described missing being in treatment and missing that routine. When treatment had ended, they missed the established order, the normal, that had become their lives.

*After I got used to it, it was just kind of like a daily thing. I don't know. It just became my normal life. I just went with everything. I got a routine of what I was doing. Bloodwork and ... routine of everything. It was pretty easy from probably a couple months after my diagnosis. It was pretty easy and just routine- it just felt normal... I just got used to having cancer and coming to the hospital all of the time. I got used to the procedures and liked coming to the hospital and seeing the nurses. I sometimes forgot about my other life as I wasn't going to school, wasn't seeing friends- wasn't playing sports- not doing the things I was doing before I got cancer.*

*To be honest, it was kind of better than I was expecting; it all happened quite orderly and expected. I didn't really have to think too much about it- it just kind of happened. I remember thinking at the beginning like how was I going to get through this long time of treatment but it actually happened a lot more quickly than I thought.*

I suggest here that for adolescents it is the cancer treatment context that is normal and the context after cancer that is abnormal (or perhaps more accurately, not yet normal). Instead of a shift during posttreatment from abnormal (cancer) to normal (life without cancer) as discussed by many adolescents in the study and a perception that is dominant throughout cancer cultural references (returning to normal etc), this shift is instead from normal (cancer) to abnormal (life without cancer). Adolescents described their lives as normal prior to the onset of cancer: *it was a normal teenage life; it was a very, very average life of a teenage boy.* The appearance of cancer

is not subtle and introduces significant changes quickly into adolescents' lives. These changes seem to transition an adolescent to a perception of abnormal initially but then, over a short period of time, the context of cancer treatment creates a "new normal" for them. This normal of cancer treatment is a context that they have adapted to and are situated within until the end of treatment. The regular routine and established order of treatment I offer facilitates the feeling of normal and the loss of this following the end of treatment, creates the feeling of life feeling not normal.

The concept of *aletheia* addresses this dual and shifting perception of normal. *Altheia* acknowledges that phenomena are complex with many angles and views. As one angle is unconcealed, another is concealed (Caputo, 1987, p. 115). It is this oscillating interplay between concealment and unconcealment that facilitates a greater understanding of the totality of an experience. In this regard, as normal recedes, abnormal comes into view. As abnormal recedes, normal comes into view. Within this oscillation, I suggest that adolescents experience a "normal" life within the context of cancer. Following the end of cancer treatment, they transition to a not-normal, and not the normal which is hoped for and assumed by many adolescents. Instead of returning to "normal" after treatment, posttreatment is a departure from the "normal" of cancer treatment.

### **Cancer as a Structure of Meaning**

Within the philosophy of hermeneutics, the world is organized into meaning relations that are both pre-established and become re-established following some sort of upheaval in understanding (Gadamer, 1960/2004). Hermeneutics responds to a world that no longer fits one's expectations and assumptions and attends to the spaces between "knowing". For many adolescents, posttreatment introduces a hermeneutic shift as they have to understand themselves in context in a new way. I offer here that the desire for normal during posttreatment that I heard

from so many adolescents in this study, constitutes a desire for a felt structure of meaning during posttreatment period of time. Throughout cancer treatment, the demands of treatment created a meaning structure that not only became established but also felt “normal”. Adolescents knew what to expect in treatment, they quickly learned its rules and demands. Cancer informed their daily routines, their social interactions, their schedules, and their time. They become quickly embedded into the structure of cancer which created a context of meaning. Within a displacement orientation, I suggest that posttreatment is also a loss of structure (conceptual place).

When describing their experience of their cancer diagnoses and treatment, adolescents seemed to describe their accommodation as an accommodation to a different culture. Adolescents are quickly oriented to cancer. Following a diagnosis of cancer, they are thrown into a well-established system of interventions, sounds, interactions and routines. The hospital environment is initially overwhelming- treatment, procedures, and new faces in a new physical environment. However, there is an established order to things. The hospital ward and clinic have a rhythm that people fall into: daily patient medical meetings, medical rounds, patient procedures and treatments, patient consultations. Adolescents who live in this space accommodate quickly and fall into a rhythm of time. Days become predictable, environmental sounds are interpreted, new faces are known and expectations for days are measured. In addition to a medical experience, cancer becomes a community for those who are impacted by it. Although the diagnosis of cancer appears to define an adolescent solely by their body and what is happening within their body, efforts are made to know the adolescent who inhabits the body. Oncology staff ask about interests, pets, school and friends. Adolescents become integrated into this community. This is resonant with Heidegger’s (1927/2010) use of lifeworld.

Gadamer (1960/2004) wrote that play is structure. What he means by this is that structure only achieves its full being each time it is experienced. In this view, a structure does not exist in itself but becomes embodied in the play. Posttreatment then is not simply a phase that one moves through but rather, it is a structure of meaning that is embodied: it is ontological. Dilthey argues that structure is “how one’s inner life is woven into (psychological) continuity” (Gadamer, 2004, p. 226). These intrinsic connections create a structural coherence of life by creating a unity of meaning that is taken up in the structures that we are at play within. Like the hermeneutic circle, this becomes the structure of interpretation. Within Gadamer’s (1960/2004) philosophy of hermeneutics, understanding always occurs against the backdrop of our situatedness which is created from history and language. This defines our horizon from which we understand within. When something novel is encountered, we approach this with our developed prejudices of understanding: our preconceptions of meaning. In this regard, adolescents confronting posttreatment experiences rely on their prejudices they developed during the time of diagnosis and treatment however, these may not fit well during posttreatment.

Posttreatment is a disruption of the normal structure of cancer. Posttreatment is not defined by any established structure of leaving many adolescents feeling disoriented and confused. When in a posttreatment period of time, many adolescents discussed missing the structure of cancer. I also offer that posttreatment may be experienced as a time of a loss of structure and a loss of the structure of cancer. Adolescents spoke to this idea of goodness of fit within structure: many did not know how they fit into their lives after treatment ended. They felt displaced between the structures of treatment and not-treatment.

## **Being-in-the-World**

Many adolescents entered into the time of posttreatment believing that cancer was over and that life could return to normal. There seemed to be a belief that the temporal progression of the cancer experience had ended and that the cancer experience could be cast aside. In contrast to their descriptions of cancer treatment as a moving forward, of having a plan, to keep going, many adolescents talked about living in the unknown and the un-defined.

Listening to many of the adolescents' narratives continued to evoke for me Heidegger's (1927/2010) articulation of being-in-the-world (dasein). With this phrase, Heidegger was expressing the very human experience of living within the world and being engaged within it. One can not choose to be in the world a different way: one is in the world and belongs to it. The essence of being he argues is existence. In this way, being in the world is not static and can't be conceptualized as a "what is it". Instead, being in the world is a self-interpreting activity that interprets itself iteratively against the background of an intelligible world. Within this interpretation, we develop and are socialized to a particular way of understanding and making sense of things.

Heidegger (1927/2010) also wrote about the impact of a world that isn't intelligible: the death of being. Although he wrote about death in a variety of conceptualizations, in this aspect, he did not mean to be biomedical or clinical but rather, death as ontological. Aho (2015) describes Heidegger's meaning of ontological death and writes that when we experience a world that is not intelligible, we experience a break-down of meaning that removes us from our ability to understand and to understand who we are in the world. He uses the term ontological death to refer to this loss of meaning of who we are in the world and more broadly, how to understand the world itself. When the world feels unfamiliar, the shared and historical background of meaning

that informs how we understand ourselves in the world, feels meaningless and “unable-to-be”. I am not suggesting here that posttreatment creates a context where adolescents are not able to be but I offer that it may create a context where adolescents are not able to be in the sense that they had expected or were familiar with. It is a context that they have not yet interpreted and they have not yet understood it.

### **Posttreatment as a Liminal Space**

I have suggested that the time of posttreatment was experienced by many adolescents in this study as a time without structure or contextual meaning especially in contrast to the structure experienced during treatment. I offer here that the time of posttreatment appears to be experienced by some adolescents as a space between: a space between structures of meaning associated with cancer. Within this space between, there is not a structure of meaning, no reference to guide them, as “normal” does not seem to fit. I offer then that posttreatment may be experienced as an in-between time.

Posttreatment may constitute a living between spaces: between the spaces of not normal (posttreatment) and normal (life beyond cancer), between being treated for cancer and being cured from cancer. Although these domains are often positioned as polarities, as either-or, there is a space between them. I offer that this is a liminal space between them and that posttreatment is a liminal period of time. Liminality is defined as ... “being an intermediate state, phase or condition; in-between and transitional” (Merriam Webster Online, 2021). It refers to an in-between state and a state that is absent of both meaning and structure. Etymologically, the term liminality comes from “pertaining to a threshold” (Online Etymological Dictionary, 2020.). A liminal space separates one space from another: it is an experience of finding oneself at a boundary or an in-between. A liminal position is both this and other, at the same time, is neither

one (Horvath et al., 2015). Liminality then is an interpreted space and is hermeneutic. A liminal space, an in-between space, is a new space for adolescents to interpret and understand. Similar to Gadamer's (1960/2004) fusion of horizons, a liminal space may be an integration of both treatment and after-treatment periods of time and a new space that is different from either.

*I felt like I belonged in treatment. When I got home, I didn't belong anywhere*

*I think I just don't know what I should do with myself now sometimes- it's harder for me to do things without my parents, I sometimes don't feel like seeing friends, I am not going to school, not working... I am just kind of doing nothing... like I am waiting... but I am not sure what I am waiting for.*

*I began noticing that cancer became a huge part of my life and it was difficult to think of my life in ways different from cancer. It was such a hard part of my life and now it's over and I'm moving on to the next part of my life and it's hard to distinguish that ... when to start this and when to end this, and I like I never thought anything would be over or that my cancer journey would be done and finished. I always thought that I would be forever marked by this ... But the hard part is, I don't know how to move past cancer. I feel like I am in the middle of this right now- like in the middle... in the middle of having cancer and then moving on past cancer. I would say maybe I'm 75%... not 50% now. About  $\frac{3}{4}$  of the way to living and getting on with life normally. It's just ... it's been a ... it wasn't hard – it was just a confusing transition to this point ... from that point to this point.*

Many adolescents began to understand that cancer was still at play in their lives even when treatment had ended. Many adolescents described posttreatment as unfamiliar and unknown. They seemed quite lost and did not know what this new way of being-in-the-world would involve. Unlike articulated aspects and phases of a cancer diagnosis and treatment, posttreatment is not yet defined through language: its absent of a social narrative describing the posttreatment time and space. Posttreatment is not a formally recognized phase or construct within the cancer experience. This made a posttreatment time difficult for adolescents to describe and their descriptions of this time within the study interviews oscillated between being in treatment and their sense of themselves in the future. It seemed difficult for them to anchor their descriptions in a posttreatment context as they struggled with language to articulate it. Liminal positions are difficult to describe in language. Their presence is both conceptualized through the opposing categories around the liminal position but also their distinctness from these categories is what creates a liminal position. However, the liminal position is more than these opposing categories (Horvath et al., 2018).

### **Liminality as Process of Transition**

The concept of liminality applied to groups of people was initially utilized within social anthropology by van Gennep. Van Gennep (1960) studied liminality within the process of transition, specifically, liminality as rites of passage within transitions and statuses of human life. He argued that within society (his work originated within tribal societies) human development involves passages from one state to another within the context of human life. His work studied transitions within the context of social transitions notably pregnancy, birth, marriage, and death. He argued that rites of passage was an essential attribute of any type of change.

Van Gennep (1960) argued that these rites of passage, each process of movement, all contained the same ordered structure of three phases and although how they are encountered differs, the basic organizing structure is universal. A successful passage then, required one to move through his proposed structural order which involved 1) preliminal rites (rites of separation), 2) liminal rites (rites of transition), and 3) postliminal rites (rites of incorporation). In the preliminal phase, one has to leave a social status behind and breaks with social and established routines and practices. In this phase, there is a separation or detachment from fixed or cultural structures and a detachment from the previous temporal-spatial setting. In the liminal phase, one moves through the threshold that marks the boundary between a previous social state and a social state to come: it is a period of transition. In this phase, one has lost the certainties of the previous state and is suspended within a period of uncertainty: there is a suspension of the ordinary and expected and one experiences a liminality in social status. It is a space of ambivalence and limbo. "The initiands live outside their normal environment and are brought to question their self and the existing social order through a series of rituals that often involve acts of pain: the initiands come to feel nameless, spatio-temporally dislocated and socially unstructured" (Thomassen 2006, p. 322). Finally, in the postliminal phase, one is re-incorporated into society into a new status and social role; essentially fitting again into a new structure of meaning. It is a return to society but in a different status.

Hockey (2002) summarizes this process as involving dis-connecting from a previous social state or position, then entering an ambiguous time where one is between social positions, and then ending with a re-entry into a new social position.

*I worry that I'll take a while to get back to where I was...like I won't be able to return. I don't really feel myself in my life and I feel behind where I should be. I'm not too worried about that because I know that I'm not bad at things. I can walk. I can work. I can think about stuff, do homework. It all just takes me longer and like I am going through a process of returning.*

*Finishing treatment hasn't been super difficult, no. I mean it kind of allows you to get back into your normal life, like you don't always have to go for checkups and stuff like that, so that's a nice thing about it. And I mean you're always ... it's a weird feeling, that's for sure. There's no other way to put it. It's a weird feeling, but it's not stressful or anything like that, at least it wasn't for me. Yeah, at certain points you kind of ... I don't know how to explain it. It's a really difficult thing to explain. You kind of ... you're not worrying about it and then a day or two later, you're kind of thinking about, "Wait. Should I be taking tests right now? Should I be monitored more closely right now?" And then you kind of ... you definitely think about it, but it's definitely not stressful. Because then you realize, okay, no ... they said I'm cured. I can go on with my life.*

Van Gennep's ideas and transitional framework fit with what adolescents in this study had shared about their experiences in posttreatment. I offer here that the ending of cancer treatment moved adolescents through a preliminal time. The meaning structure and practices that they came to understand and integrate during their time in treatment, were disrupted following the ending of treatment. When they had finished treatment, they had to let go of these meaning structures and practices and transition to a social status. Posttreatment then constituted a liminal time. Van Gennep believed that liminality is temporary and eventually one returns to an expected

structure of life. He argued that this transitional process results in a re-orientation to new social statuses. In a postliminal phase, adolescents would re-orient to new social statuses and have re-structured social roles, community and structures of meaning as time moved on beyond posttreatment.

### **Liminality as Disruption**

Liminality has also been conceptualized as a time of disruption and the creation of alternative structures rather than a structural process of transition. Turner (1979) argued that liminality refers to any in-between situation and can refer to single moments or longer periods of time. He defined the liminal space as one that is "betwixt and between the normal, day to day cultural and social states" (Turner, 1979, p. 94). This space is one that is on the margins and this marginal social location can create feelings of "ambiguity and paradox" (Turner, 1967, p.97). Turner believed the liminal space to be a place of disruption: a break from normality. Although Turner conceptualized a liminal space as marginal, he believed that a liminal space held transformative possibilities: it held potentialities of forming alternative structures.

Turner argued that this space is one where this ambiguity may reverse individual roles or social status and culturally recognized positions are often no longer relevant. It is a time of transformation as the liminal position is neither the previous social structure nor the future newly created or integrated one. An individual who moves to the liminal phase finds themselves in the gap between worlds, or within a certain medium between the alternative structure of 'here' and 'there' (Palmer, 1980, p. 8). Turner's concept of liminality highlights the interaction and confrontation of dominant social ideologies (beliefs, expectations etc) and their suspension within a liminal space. Where Van Gennep had studied rites of passage typically involving social events and thus a change in social status, within Turner's work, rites of passage were not

restricted to movement between socially ascribed statuses (birth, marriage etc). They also included new achieved statuses (Turner, 1967). According to Turner, all liminality is temporary and must eventually dissolve as the liminal space feels too acute and one can not exist long in this liminal space without some sort of structure to stabilize it. He believed that either the individual returns to the previous surrounding social structure or else liminal communities develop their own internal structure which is what he referred to as “normative communitas” (1967). This is a shared group feeling of connection with people experiencing the same liminal experience.

*I am still getting used to these changes and trying to understand them. I feel very apart from my life before cancer and who I am now- my lives feel very different. I felt very out of the world when I was in the hospital and it's been hard to get back into the world.*

*And I guess like that has been kind of like the crappiest part but like when like the first month or two after treatment, I was so happy I was I was really like excited. I was like, relieved. I didn't have to like go every week for an appointment anymore. And then I could like start moving on into bigger and better things. But recently, it's been kind of hard to say the least, like having to just sit around and wait.... And honestly, I am not even sure what I am waiting for. I just don't know what to do- I not going to school, I am not working and my body feels terrible. So I just feel like I am helplessly waiting for life to start again....It's just been really hard because I thought that life would feel like it was moving forward after treatment- like this new chapter of my life would be defined right now. But instead, I feel caught in a book with many chapters and I really don't know in*

*which chapter I am supposed to be in. Life is moving so slow for me right now and I don't like it.*

*When I entered treatment, I felt like after, it was just going to be, like you go back to normal, like how things were before. Like, you can go do sports, you can, you can work a part time, full time, whatever job, you can go to college and not worry about, like the side effects or whatever, like things go back to normal, but it just, it's just not normal. And I guess after something like cancer, things don't go back to normal. Like, I still, like would still be engaging different with my body and thinking about my body after treatment. Like, I thought life would be different and that I thought it would be back to a pre treatment world.*

Turner (1967) believed that a liminal space is more than just a space between a beginning and an end: it is more than a transition. Instead, a liminal space is an experience of suspension and ambiguity. He writes that liminal people are structurally invisible: they are without role or status and are on the margins. The posttreatment challenges experienced by some adolescents are invisible: in this way, these adolescents are structurally invisible. They are neither patients nor non-patients: they are in-between.

Turner's comments about "normative communitas" resonated with my clinical practice observations about adolescents in this posttreatment time. Given opportunity, adolescents diagnosed with cancer form strong peer relationships with other adolescents with cancer. They develop a community of belonging and validation that extends beyond what clinicians could provide for them. I am reminded of the teen group that I started twelve years ago for adolescents diagnosed with cancer. This monthly group drew a diverse group of patients: on-treatment and

off-treatment, newly-diagnosed, and palliative. Despite their medical and social differences, they were united, they were a community. Many adolescents continued to attend teen group years beyond their diagnosis. They felt joined to this group of people: I believe they had created a normative *communitas* as a structure of meaning. One adolescent brought up this teen group in their interview: *We're kind of like a special group of teens who battled and persevered through so much. It's nice that there are people who know what I've been through and who can kind of pat me on the back and say you made it.*

### **A Liminal Position: Cancer Patient- Not Cancer Patient**

Liminality has been suggested by others as a relevant framework within which to understand the cancer experience (Blows et al., 2012). Within the context of cancer, Little et al. (1998) propose liminality as a major category in the cancer experience. As opposed to a disruption that people move through and recover from, they argue that the experience of illness introduces permanent changes to one's state- that one lives in a permanent liminal state following the end of cancer treatment and for the rest of a patient's life. Following a cancer diagnosis, they argue, that all patients enter and experience liminality and remain in a state of sustained liminality where people continue to construct and reconstruct meaning of their experiences. They believe that liminality becomes a long-term and permanent existential state for those diagnosed with cancer and is enduring even for those without lasting medical effects or disability from the cancer diagnosis.

I suggest that many adolescents in this study experienced posttreatment as a liminal period of both disruption and a process of social passage: disruption might be part of this social passage. Adolescents spoke clearly of the disruption of posttreatment and the disconnection they felt as this time felt unknown to them. It is also likely that liminality will be experienced as a

process of passage. This study only included participants up until 18 months following the end of active cancer treatment. It is unknown how the process of this disruption will be managed by them over time. In Turner's view, liminality is finite and one is reintegrated back into society. For many adolescents in this study though, they are in remission from their disease which is a space of betwixt and between. In remission, one is no longer in treatment but one is not free of a disease status: they sit in the space of in-between within cancer.

I have proposed earlier that the posttreatment space is absent of a social structure of meaning in which to orient and locate an adolescent who has completed treatment for cancer. I offer here that the liminal space experienced by some adolescents is between having cancer and not having cancer: between being a patient and not being a patient. An adolescent who has completed treatment for cancer lives between spaces: the immediate space between on treatment and being off treatment but also within the broader spaces of illness and health. Adolescents did not know how to define themselves during a posttreatment time. They are neither cancer patients nor people free of cancer: they are stuck in between. They straddled both worlds of the sick and healthy and yet were located in neither and did not fit with either group.

Within this space of in-between and within neither, there is no structure to support their interpretations and experiences. The off-treatment experiences are complicated by the medical intervention that continues to live in the lives of people who have completed treatment. Although this intervention is much less intense, it exists and marks someone as a patient. For many adolescents, there appeared to be a persistence of cancer patient-ness even when cancer treatment had ended months prior. Although they had re-entered aspects of their life: school, peer relationships, they felt connected to the experience of cancer and other cancer patients. They seemed to arrive at a certain image of themselves as cancer patients that was maintained as they

re-engaged other aspects of their life. In this way, adolescents moved through cancer but did not return to the space occupied prior to the diagnosis.

*I mean, it'll always be a part of me, and I think I will always feel that. And because I still go in for checkups every six months, that's what I kind of reference by the road is still going. But like I feel physical physically, I've caught up. And mentally I caught up too. I am feeling better emotionally and so there's no reason to feel disappointed in myself, that I've failed at anything. Because that's how I did feel like I always wanted to catch up, and I was just unable to do that. I wanted to catch up but I didn't know how.*

### **A Brief Acknowledgement of Identity**

This chapter has centered around the loss of structure as meaning during a posttreatment period of time. Unlike challenges to identity, many adolescents in this study seemed to have a coherent identity through treatment and in posttreatment, they just did not have the social structure to catch them during the move to posttreatment. Zebrack (2000) suggests that a new identity develops, or is reconstructed, following the experience of cancer. Following a diagnosis of cancer, people see themselves differently in relation to the world and others around them. Within the experience of cancer, their social roles change and this impacts their sense of personal identity. He argues that the experience of cancer creates a new social role of cancer survivor that becomes integrated into identity and remains part of one's identity over the remainder of one's life regardless of life expectancy. However, his discussion is focused on the experiences of adults diagnosed with cancer and he did not address adolescents.

In my study, adolescents seemed to have a strong sense of who they were and were not overtly engaged in identity exploration within the specific context of cancer. They seemed to know who they were before their diagnosis and after their diagnosis: they just did not have a

structure of meaning to fit into within posttreatment. This aligns with other research with adolescents diagnosed with cancer. Adolescents reported that they do believe they are the same person that they were prior to their diagnosis even though they may not feel or look normal (Larouche & Chin-Peuckert, 2006; Woodgate, 2005).

Instead of identity, there also seemed to be a discrepancy between beliefs of representations of their self. Within this posttreatment time, many adolescents seemed to experience a discrepancy between their actual/own self-state representation and an ought self-state (attributes that they believed they ought to possess) (Higgins, 1987). They believed, and others also believed, that they should be back to “normal” and successfully re-integrating back into their life. The pervasive message of returning to normal I offer challenged the actual self-state in this liminal space and created incompatible beliefs between where they were liminally and where they wanted to be post-cancer. Within this discrepancy, Higgins (1987) has found a relationship with negative impacts to psychological well-being. Although articulated in the language of identity, a study on adolescent survivors described a similar in-between experienced by adolescents treated for cancer (Jones et al., 2011). The authors of this study argued that adolescents were caught between their identity as a cancer patient and their identity as a survivor. They describe this identity as paradoxical: identification with both a cancer social group and a cancer survivor social group. They are each and they are both.

### **Ritual as Transition**

*There was a little ritual at the end of treatment, every kid at the children's hospital gets to ring a bell. So that I guess that kind of signifies the end. But I didn't really see that as the end because I knew I kind of had a hard road in front of me. I mean, I'm technically*

*still on that road, to a lesser extent, but fresh out of the hospital, it's really hard to adjust to life. So I didn't really see it as that much of an accomplishment.*

Finally, to Turner (1959), a liminal space is one of anti-temporality: it is a cessation of the previous temporal setting of movement. However, this shift occurs within the context of transition. Within transition, there often exists rituals to mark this movement. Within liminal spaces, rituals hold meaning in and are utilized to mark social passages. Van Gennep's (1909) belief in rituals as necessary and transformative of social passages has struck me as significant within the posttreatment context.

Within a pediatric cancer context, the marking of the ending of cancer treatment is accompanied by rituals. For example, a bell is rung and as other adolescents have discussed in their interviews, trophies are given to both the patient (child/adolescent) and sibling(s). These rituals are formal markings of something significant- something outside the typical. Horvath et al. (2015) notes that humans tend to ritualize and symbolize these kinds of significant moments. The practice of ritual symbolism can be understood as a representation of a liminal passage.

The etymological roots of ritual lie within realms of religion. The word ritual comes from the Latin word *ritus* "religious observance or ceremony, custom, usage" (Online Etymological Dictionary, 2020). This offers a perspective into ritual as ceremonial: a ritual as sacred. Rituals are not just how reality is decorated but rather, rituals reflect reality. Rituals shape and form people going through liminal experiences (Horvath et al., 2015). In this way, rituals needed to be attended to with care and intention because they leave an imprint on those who receive them.

One adolescent spoke strongly about the pervasive impact of the lack of acknowledgement that her completion of cancer treatment elicited from her oncology team: their communication to her of their understanding of the meaning of finishing treatment for a life-

threatening disease and their understanding of the meaning of going through cancer treatment for her.

*I imagined what it would be like to end treatment and how amazing that would feel. In some ways, my end of treatment just felt like another chemo date. So it was it was very anticlimactic for me, it was a 15 minute appointment where I got to see my oncologist for 10 or 15 minutes. And it was just, it kind of fizzled. If you if you get what I mean- everyone seemed busy and I didn't really get to see many people that I had seen for so long and then we left. And I don't know. Like, I'm happy to be done... I don't know. Like, I'm not sure if I feel like maybe I would have more closure over it. Because it was like it was a big part of my life for a long time.*

*Which I've told myself sounds stupid to have closure over something that was so hard. I think it was just hard not seeing the staff regularly- people I had spent so much time with. I didn't get to see my favourite Dr and say "Hey, I am DONE! Like, you don't got to see this ugly mug no more kind of thing". Like, I didn't get to do that. So it's just difficult. I think it was important... like, for this ending of treatment to be acknowledged, to be acknowledged that I did well, I guess, that I made it. I don't really know how to explain it. But to really acknowledge that I was done like it was a big accomplishment or something.*

Although she did not use the term ritual, I believe this was her meaning: a sacred ceremonial rite of completing treatment. While discussing her experience at the end, the final day of treatment, she was very upset and crying throughout her description. I became aware of this as another loss for her: the loss of ritual as important marker of her passage throughout a cancer diagnosis and treatment. These rituals that mark an ending, a sacred passage, must be tended to

in the way that this is recognized. These ritual practices imbue meaning, imbue meaning in the context of completing treatment for cancer, and I offer, intentionally done, signal the cusp of a new transition: a life after treatment.

### **Final Thoughts**

Gadamer (1960/2004) argues that understanding is shaped by tradition and language: this constitutes our being-in-the-world. “Survivorship” represents a tradition of understanding the experiences of people who have completed treatment for cancer: adolescents are situated within this tradition. Tradition though is not repeated but changed and modified, reworked and reinterpreted. Rather than distancing or freeing ourselves from tradition, hermeneutics lets us be aware of our historical judgment, makes us conscious of the prejudices governing our own understanding, and helps us in “foregrounding” it: traditions are open to change.

Within this chapter, I have created a shape for the posttreatment experiences of adolescents following cancer. I have offered interpretations surrounding both displacement and liminality as informing these posttreatment experiences. These offered interpretations are not “the” shape, but a shape, of posttreatment and I have outlined the context within how I have come to understand this shape.

Posttreatment is not understood as a defined part of the cancer experience. Anecdotally, it is not often considered as a transitional space. Yet I have discussed within this chapter that posttreatment is a unique space within which adolescents who have completed treatment are located. Posttreatment is hermeneutical: it is space that needs to be interpreted, and subsequently understood, by adolescents who move into this time and the health care clinicians caring for them. The narratives I heard by adolescents within this study expressed the complexity of this posttreatment time. Their words have lingered with me and the dialogue I have had with myself

in this context has further enlarged my understanding of this hermeneutic space and how I might attend to this space as a clinician. The philosophy of hermeneutics challenges phenomena as understood in their totality and my hope with this chapter is that it contributes understanding to both how adolescents experience living within liminality and how the shape of their experience may change following the completion of cancer treatment.

## Chapter Seven: Feeling Far and Near

*I am so used to people not understanding what I have been through... and really, not understanding me. I don't blame them for that, how could they understand? But during my first teen group, I came home and I started crying to my mom. I told her "THESE people (other adolescents diagnosed with cancer) really get me!"*

(Adolescent participant, age 17)

### Introduction

This chapter is the third interpretive chapter of findings within my dissertation. It explores adolescents' experiences within social connection with others following the completion of cancer treatment. I have titled this chapter "far and near" because instead of positioning these terms as dichotomous as they often are considered, far or near, I will discuss adolescents' experiences of feeling both far and near to those around them during posttreatment. The playfulness of the phrase "far and near" reminds me of Gadamer's (1960/2004) articulation of the primacy of the structure of play in understanding. Play discloses the full context of a topic and supports different possibilities of contextual understanding: within play, there are different opportunities to understand.

Following a diagnosis of cancer, the social worlds of most adolescents change quickly. Many adolescents are plucked out of their social worlds and are confronted by a new one within the cancer treatment context. For most adolescents, cancer treatment requires extensive time in hospital and in out-patient treatments and appointments. Due to their cancer treatment and its medical impact, adolescents spend long periods of time in hospital, at home, and away from school. Within these contexts, they are often physically isolated from some of their previous relational network. Many adolescents also need to travel away from their home community for

long periods of time and are separated from family and community members. They often spend the majority of their time with parents and health care staff and much less time with friends and peers.

*I mean just in hospital I've been like away from the outside world for so long, so coming back to see what it is now that treatment is done was really hard. Like what changed and yeah ... just a lot of things going on – like in the hospital room, I am with the laptop, my phone, and a TV. And my family, of course, but that's about it. I couldn't see anything outside of that. It's kind of tough seeing what was going on out there.*

*I was alone during my treatment and was in the hospital for a long time with just my mom and didn't have my friends around. I almost don't know how to make friends anymore or be with them- I feel more sad than I used to and probably not fun to be around.*

### **Social Relationships of Adolescents with Cancer**

It is not my intention to offer here an exhaustive review of the psychosocial oncology research regarding the social relationships of adolescents diagnosed with cancer. Rather, I want to briefly establish the current horizon of understanding of this topic. After a cancer diagnosis, many adolescents experience changes in their social relationships. Much of the research on the social relationships of adolescents following a diagnosis of cancer, have most often studied adolescents' perceptions of the quality of, and changes to, the supportive nature of these relationships throughout the cancer trajectory. The impact of a cancer diagnosis is believed to create non-normative disruption to adolescents' relationships with parents and peers. The extended time that adolescents spend with their parents during treatment and the reduced time

that adolescents spend with peers, creates conditions for adolescents to lose independence and to become increasingly reliant on their parents (D'Agostino et al., 2011; Grinyer, 2007).

Like adolescents without a cancer diagnosis, many studies have found adolescents experience their parents to be supportive and they experience satisfaction with these relationships. Adolescents perceive and experience strong supportive relationships with their parents, especially their mothers, throughout cancer treatment (Decker, 2007; Haluska et al., 2002; Kyngas et al., 2001; Woodgate, 2006). Adolescents with cancer perceive strong social support coming from both their family and friends (Decker, 2006; Woodgate, 2006) which is congruent with adolescents without a diagnosis of cancer (Haluska et al., 2002). However, within the cancer context, relationships with friends were found to be less satisfactory than those with parents (Decker, 2006). Relationships with friends were found to be variable with support shifting as time extends beyond the cancer diagnosis and friends not knowing how to support a diagnosed adolescent (Enskar et al., 1997; Kaluarachchi et al., 2020). Relationships with friends were found to be both valued and challenging following a cancer diagnosis and adolescents have identified: “being there” (Woodgate, 2006), feeling connected, support and understanding, and normalcy, as dimensions that they consider as important within relationships with friends within a cancer context (Kaluarachchi et al., 2019).

In this study, some adolescents did not perceive any differences or changes within their relational connections with friends and family. Some experienced these relationships as unchanged and not impacted from their cancer experience: *we are all still friends and we talk pretty much every day; nothing really has changed with my family- we are all pretty close.* Within some of these narratives, there was the thread of returning to normal as I discussed within the previous chapter. *My friends understand what I've been through. We don't really talk about*

*it. I'm pretty grateful for that. Yep. I just wanted to go back to the way it was – that's why I did everything to kind of get my old life back and I didn't want to talk about what I had been through.*

Reading these words I am struck again by the strong desire of some adolescents to return to normal: as though to reveal parts of their cancer experience may conceal parts of their “normal” self. This is similar to the previously discussed hermeneutic idea of aletheia: keeping certain parts out of view, leaves other parts to feel constitutive of the whole. Frank (2013) discusses the restitution narrative as one of the dominant illness narratives at play during an acute health experience. He describes the restitution narrative as narratives that focus on recovery towards health: recovery being the sole focus of attention within illness. He describes this orientation towards recovery from illness as both socially sanctioned and propagated by social narratives, medical institutions, and patients themselves. Restitution stories, often containing metaphoric phrases such as “back to normal” continue to reinforce and re-situate patients within the restitution narrative. The meaning of the term restitution is Latin in origin and involves the prefix re meaning “again, to a former state” and statuere “to set up” (Online Etymological Dictionary, 2020). This setting up to a former state, this return to a former state, I offer is a desire for restoration of aspects of life, of relationships, prior to their diagnosis of cancer. With the expectation of returning to “normal” as discussed in the previous chapter, for many adolescents there seems to hold the implicit expectation that relationships with others will also feel “normal”.

### **Feeling Far**

#### **Loneliness**

*I was gone from school for so much of the time my friends kind of drifted away. Um, and so I like, had a kind of lonelier grade 11 and grade 12 year...I was lonely for a long time. Afterwards, because I didn't really, I had to make new friends and stuff because my friends would stop kind of hanging out with me. Um. And then, like, you know, you're kind of nervous and you don't really know how to do things quite like your friends.*

*Well, there's a lot of bullying. Like I was on steroids and prednisone, so it makes me kind of big. And I eat a lot and so I got teased for being fat and I ended up changing schools. This school is better that I'm now in, but kids just don't understand what you're going through and it's just kind of tough because they don't know what you're going through in your life, what's going on. I had tons of friends in my old school. I find like when I got diagnosed, a lot of them just moved on and just left. I don't know. That was really hard but I also didn't have time to deal with that.*

*I feel very lonely right now. I don't know what to do about that. (Is crying). It's like every day I need to think about being fun and happy but that's really tiring and hard. Before cancer, I felt happy and was busy, played lots of sports, had friends, school was stressful but it was ok.*

Posttreatment can be a lonely time for adolescents: many adolescents in this study felt far from others. Loneliness has been defined as the experienced state when a discrepancy exists between the relationships one wishes to have and those that one perceives they currently have (Peplau & Perlman, 1982). Research has shown that adolescents experience more frequent and

more stronger experiences of loneliness than older adults. Approximately 19% of adolescents, without a history of illness, experience loneliness (Bayat et al., 2021).

Although conceptually loneliness isn't defined as solitary aloneness, many adolescents in this study experienced loneliness that way. Loneliness throughout their cancer experience was often named and described by many adolescents as the experience of being physically separated from others: they felt physically alone and solitary. They felt socially isolated. For many adolescents, the loss of relationships, and the change in the quality of their social relationships, were experienced as loneliness and separation from others. At different times following a cancer diagnosis, adolescents are separated from certain members of their family, their friends, and from the relationships they developed within hospital. During posttreatment, adolescents discussed the loss of relationships with peers and with the oncology clinicians who had cared for them. Friends did not relate to them in the ways they had assumed they would and some grieved the loss of relationships with oncology clinicians that had become central to their treatment experiences.

I offered in an earlier chapter that as Heidegger (1927/2010) suggested about our situatedness in the world, adolescents are thrown into the experience of cancer. They are also thrown into posttreatment from the context of treatment. Heidegger writes that one is taken over by its world and absorbed by it. He refers to this experience as facticity: something that already informs us and that we have taken up, even if it's unnoticed or un-attended. Within this integration of contexts we are thrown into, we are also thrown into relations with others (George, 2020). Adolescents are thrown into the new context of posttreatment with new social relations to navigate.

### **Feeling Alone**

The articulations of their experiences of loneliness described by adolescents in this study- feeling physically separate from others- did not fully capture what I was hearing and reading in the dialogues within this study. I suggest here that other aspects are at play within adolescents' contextual experiences of loneliness during posttreatment. The term loneliness is made up of the root word of lonely (Online Etymology Dictionary, 2021) and it's the consideration of this term lonely, and its meaning, which offers another portal to understanding adolescents' relational experiences in a posttreatment period of time.

Something different can be understood about their experiences in social relationships following the completion of cancer treatment when considering the etymological origins of lonely and alone. Although definitionally similar, etymologically, there is a subtle difference which offers a resonance to the experiences of some adolescents during posttreatment. Definitionally, lonely is understood as "being without company, cut off from others" (Merriam Webster Online, 2021). Alone is defined as "separated from others" (Merriam Webster Online, 2021). These definitions are similar and reflect the narratives of many adolescents in this study. Etymologically though, there is a slight distinction between these terms. The term lonely originates from the 1600s and involves a feeling of "solitary, lone; unfrequented" (Online Etymology Dictionary, 2021). The etymological origins of alone, although historically involving solitary within its meaning, also includes "unaccompanied; without companions" (Online Etymology Dictionary, 2020): alone is the feeling of being unaccompanied. I suggest that many adolescents feel alone during posttreatment and that posttreatment is a time where adolescents feel unaccompanied and without companions.

### ***In-Treatment***

I suggest that this lens of companionship is implicit within all of the established recommendations, priorities, and guidelines developed for the support and psychosocial care of adolescents within a cancer context. It is understood that adolescents are often without companions following the onset of cancer and that adolescents and their families need companionship following a cancer diagnosis. They are separated from family members, friends, peers, and their community. Their parents are also thrown into the experience of cancer and may not be able to accompany them through the beginning of cancer treatment. Oncology staff are positioned to accompany adolescents and their families through treatment. Within cancer treatment, adolescents are accompanied closely and continuously by the staff caring for them. Many adolescents spoke about the meaning and support derived from these relationships with the nurses and physicians caring for them: *I love my nurses: I don't know where I would be without them; I miss my Dr- it's strange to say you miss your Dr but I miss him... he helped me and family so much.* In addition to the companionship offered by oncology staff, adolescents are rarely apart from a parent(s). Parents join them for hospital admissions, clinic visits, remain with them at home. They remain in hospital with their parents and when at home, are closely supervised and in close proximity to their parents and other family members. They spend little time away from a family member. Although some adolescents interviewed experienced a loss in relationships with friends and peers, others maintained that these relationships continued. Many adolescents discussed the endurance of their relationships with friends throughout their treatment and the significance of this presence. *Also, just the importance of having friend around. Seeing my friends was a huge thing, because I knew that at one time, we were the same. So when I saw them, I just thought, I'm gonna get back to that point one day. They were kind of my measuring stick.*

Within a cancer context, as I have addressed in a previous chapter, there is a sense of community. This community offers acceptance, support, and normalization: it offers companionship. This community is made up of oncology clinicians and the other adolescents and families undergoing cancer treatment. One participant described the significant meaning for her of being part of this community: she described belonging to this community in oncology as the “best part of cancer treatment”. Within this community during treatment, she did not feel alone.

*But it was a good time in my life when I had a community that I could rely on. Because like, I had people who've been through it, who may have been younger than me, like, a lot of my friends, when I was going through treatment were like, 13, 14 (age), like, they were quite a bit younger than me. But like, we shared experiences, like having certain side effects from certain chemos and stuff like that.*

*And I remember them all being like so like, thankful that I was like, out of the hospital and like just like, I don't know, feeling a bit more community while down there compared to now when I am home. And I guess I kind of missed that during post treatment: I missed being a part of that- like being a part of community.*

### ***Posttreatment***

The loss of community for another participant was very difficult during posttreatment. She spoke metaphorically about its loss but also very concretely about it- the grief she experienced learning of deaths of adolescents who made up this treatment community. For her, this was one of the hardest aspects of posttreatment: losing these companions.

*But I still feel bad for some of my friends who are going through it. Because I'm done. And they're still going through it. I just I think it's like survivor's guilt, kind of but like...(she is crying)...it's hard because some of the people who I knew during treatment like.., since I've ended, they haven't made it. So they earned their wings. And so that's also really hard. That's, that's probably the worst post treatment thing. It does feel harder now that I am done treatment: in treatment, I got to see them more, I got to see them, like, before they died. But being posttreatment and not seeing them in a long time and then finding out like, what's happened is really hard, because you can't be there with their family and like stuff like that. You didn't get to see them before they died (crying).*

During posttreatment, many adolescents are unaccompanied: they are without companions. Some parents return to work and adolescents have more solitary time at home. Many adolescents return to school but often find school and peer relationships confusing and isolating. Friendships may feel different as neither adolescents nor their friends know how to navigate the time of cancer. Many adolescents experienced changes in friendships and difficulty in connecting with friends. Many adolescents also missed the relationships of oncology staff: they discussed feeling forgotten by their oncology team. One participant in this study described the necessity of counselling support during posttreatment: and the need to provide training to oncology psychosocial clinicians to be able to deliver this effectively: she did not feel the support she received was adequate and I suggest, she continued to feel unaccompanied. These changes in relationships were experienced as losses and they were losses many adolescents felt un-prepared for.

*But I know for me personally, it's really hard because I, I found a lot of comfort in my team. And I'm sure a lot of like, people who've gone through it have a lot of comfort in*

*their team, and really respect them and have a fun time with them and everything. But yeah, that's that's sort of another thing that is kind of hard. Posttreatment is going from seeing like, someone you tell everything to like, right down to "how are you pooping and peeing", you know, like, it's kind of like, you don't really, like hide anything from them and, like that kind of stuff. So it's kind of hard from going to tell someone everything like, quite literally, to not barely even emailing back and forth. So that's really difficult. That was a surprise.*

*Well, like I felt excluded. I mean, obviously, my friends were inclusive, and they were super nice to me, because they knew my situation, but I always just felt like I couldn't do as much as them. I didn't feel like one of them. And so I felt really different from them after my diagnosis- like I didn't really fit.*

*And so I guess that was really hard for me to see like how my friendships changed a bit because of being sick. Nowadays, because I don't appear a sick or it doesn't look like I had cancer, there's really only one thing on me that tells someone that I did. And that's a scar that you can't even see. So friendship wise, it's been really like tough on old friendships and new ones when it comes up in conversation.*

Heidegger (1927/2010) argues that being in the world is being with others: being with others is an ontological determination of being. In this perspective, being alone is a deficient mode of being-with and holds implications for one's being (Costache, 2013). With the term "alone" he does not mean solitary, but rather a loss of engaged presence. Gadamer also understands loneliness as the experience of loss: the loss of shared experience and communal

presence. He writes “To stand in a common sphere and to be supported by something communal- this is what we decry when something disappears or is lost in the sadness of loneliness”

(Gadamer, 1988, p. 102 as cited in Costache, 2013).

I offer that adolescents experience the loss of being communally accompanied during posttreatment. Heidegger (1927/2010) writes that being-with others is being with people that one can not distinguish oneself from. Being-with is not objectively with but rather a feeling of being connected to others in everydayness. This feeling of being connected to others in everydayness I offer is what adolescents experience in treatment: connected to family, staff, and other adolescents and families undergoing cancer treatment. This idea of being-with is experiential and within posttreatment, a less familiar world is encountered with new everydayness. The implication of Heidegger’s argument is that existing is inextricably linked to being with others. It suggests then that when one does not feel connected to others, this has impact to one’s (well)being. I suggest that a loss of companions, is an impact to wellbeing.

### **Feeling Othered**

*I like my friends at camp (camp for adolescents with cancer). They’re so special. And they, they support me so much. And we were like, super close and stuff. But you know, friends in the outside they are really nice but they just don’t understand as well. The friends from camp you have so much more in common with. Like my camp friends if I say “my VAD flipped out and it’s not in anymore!” they will resonate with that. But my non-treatment friends, they just don’t get it.*

*All of my friends have been super, super respectful and they’ve all helped me out through this. But I mean, unfortunately... well, not unfortunately, but life goes on for them, life*

*doesn't go for you in the same way. And I've had a couple friends that have been texting me every day asking how things are going, talking to me through like video game consoles, facetimeing me, and just spending time with me and really caring, but as soon as you click the off button, their life continues in the same way and your life doesn't.*

*And when I was walking down the hallways, everybody was kind of respectfully but just kind of looking at me... and I could tell they were thinking "Ok, that's the kid who has cancer".*

Many adolescents discussed feeling separate from their peers following the end of treatment. Statements of goodness-of-fit were both directly shared and interpretively nuanced. Many felt different from their friends and peers: as though they did not fit with them. Although many adolescents discussed the loss of peer relationships over the course of their cancer treatment, other adolescents described relationships that did not end but instead, seemed to pause: to pause around the treatment of cancer. In these relational contexts, adolescents described their friends and peer relationships as supportive and their perceptions that their friends were trying to understand them. Yet, they also perceived that their friends were not able to. Following the end of cancer treatment, the relationships were still there, but many adolescents did not know how to embody them the way they had prior to their diagnosis. These relationships, while experienced as supportive, were also experienced as a distance and a separation, and I offer an inability to be understood when treatment ended and life should be getting "back to normal".

"That's the kid who has cancer" as referenced above was a phrase that was evoked both directly and indirectly within different narratives shared by adolescents in this study. This phrase

suggests that some adolescents felt different from their healthy friends and peers. I suggest here that many adolescents following the completion of cancer treatment and a return to other social contexts, feel othered. Specifically, they feel othered by cancer. Attention both conceptually and pragmatically to “the other”, and responding to the other, has been taken up quite extensively within both philosophy and anthropology. Othering is both a historical and contemporary practice and has been understood within a variety of ontological positions (Kearney, 2003). Kearney (2003) discusses how Western culture interprets the other. He identifies the guises of strangers, gods, and monsters as figures of otherness that society has created to understand those perceived as different. I suggest not that the othering of adolescents is due to one of these categories of culturally-interpreted otherness, but rather, that cancer creates a new category of “adolescent” that both adolescents who have had cancer and non-cancer adolescents have to interpret. Cancer others adolescents and it’s this othering, I offer, that creates a context for adolescents to feel that they no longer fit with their non-cancer friends. This is a new horizon for adolescents and their non-cancer friends to navigate.

Hermeneutics leans into the experiences of strangeness: the shared space of the familiar and unfamiliar. It is this space of the other and the non-other that I offer adolescents confront when they are done treatment. They are both adolescent and adolescent who has had cancer: they are both and either. This dualism supports both the feeling of a non-other and other which was reflected in the narratives of many adolescents. Alterity is a term that describes otherness and feeling othered. As a philosophy, it has deep roots in phenomenology and refers to something that transcends one’s grasp (Leistle, 2017). This is aligned with phenomenological intentionality in which something may not be perceived but the subject holds a mental representation of it (Moules et al., 2015). I offer that cancer leaves many adolescents marked by alterity. Waldenfels

(2011) argues that the other as alien is a central theme in mental health: that which is perceived to be other, to be different, is alien. He describes degrees of alienness of everyday alien (neighbour, cashier), the structural alien (exists beyond the boundaries of established/expected social life- immersion in a different culture etc) and radical alien (transforms interpretations- experienced in pain and illness, birth and death etc). Within this idea, the other is socially estranged within contexts of illness. Different from Waldenfels' (2011) argument above, adolescents in this study did not feel estranged following a cancer diagnosis or within treatment, but many experienced degrees of estrangement following the completion of cancer treatment.

### **Feeling Near to Others**

The above sections addressed the experiences of separation and disconnection that I heard from many adolescents in this study. Many adolescents though also feel close to others during posttreatment: they feel both separate from, and connected to, others. This present section attends to their experiences of relational closeness.

*Before diagnosis, I never really thought about what people go through and it sounds rude, and I don't mean it this way, but I didn't really think about other peoples' problems in this kind of sense. I didn't think what that really meant, I just knew that's "too bad, I'm sorry". But now I know what it's really like to be in those kind of situations and there are things before that I didn't think ... mattered as much as I do now. Like I knew the Terry Fox run mattered, but I didn't really know what it was fighting for. A lot of different things: I think now I'm more open to understanding what other people's struggles are like and how things really affect other people.*

*I felt like I also knew more about other people, like what they might be going through. I never really thought of it before and so this was different...other people going through anything really. Diagnosed with cancer, yes specifically, but anybody that goes through anything medically – like my friend has ADHD and I never really thought about how that must have been a struggle for him. I mean I don't have that, but I kind of knew what it was like to be struggling with something like that – something that you just couldn't control.*

*Also, having cancer, I think grew my empathy as a person. Like, I know how bad it is for people sometimes. And you just get this feeling like you want to help people. Because you now know, the pain that someone goes through people. But I don't know. I know, there's not much to add on that. But I, I'd say empathy was the biggest one. I think I just didn't think a lot about other people and their lives before I got cancer. In some weird way, having cancer actually made me a better person because I think I am more caring and have more empathy for people.*

Many adolescents discussed the enhanced compassion and empathy they now felt as young people who have gone through something as difficult as cancer treatment. Some adolescents described their acknowledgement of and self-identified greater compassion for their parents and siblings:

*I was so scared for my mom after my cancer diagnosis; My mom said that, to see me go through high school and start university she was like, amazed, she was just like, “you go, girl, you got this”. Like, she was, she was really proud of me. Um, and, I asked her, “well, you know, like, you're proud of him (sibling), too, aren't you?. And she said,*

*“yeah, but he didn't have the same kind of, you know, obstacles in his way, you know”.*  
*But, I think it's important for him to get recognition too: my brain tumour was hard for him too.*

Many adolescents spoke about deep empathy for their parents and described their understanding of their parents' distress and suffering within the context of their cancer diagnosis and treatment.

Interestingly though, it was their enhanced attention to the suffering of others that they did not know, to the suffering of strangers, that seemed to grab their attention most strongly. To many adolescents in this study, the experience of cancer treatment offered a shift in perspective towards the other. The experience of cancer, of moving through a cancer diagnosis and treatment, enhanced their ability to see and understand the other and to see the other when suffering. Many adolescents spoke about this opening of empathy: this opening to seeing others struggle. Within their narratives, they also offered a distinction between sympathy and empathy: between “too bad I'm sorry” and “know what it's really like to be in those kind of situations” as stated in the above narratives.

Empathy has been addressed within philosophical hermeneutics. Husserl writes that another is experienced as an object of perception and then through empathy, becomes a subject to understand. However, this conceptualization maintains a return to the individual self which Gadamer argues is not true hermeneutic understanding (Gadamer, 1960/2004). Risser (2019) articulates Gadamer's use of the word *sunesis* as a concept of empathy. *Sunesis* is not the ability to be connected to other by way of sympathy. Instead *sunesis* is a commitment to the view of another which is only possible if “one and other are bound together from the outset” (p.10). I offer that cancer creates the opportunity for *sunesis* for adolescents.

Gadamer writes about another concept which I offer is at play within adolescents' experiences of feeling close to other during posttreatment. Risser (2019) argues that Gadamer's hermeneutics is concerned with the opening of shared life in which one is able to hear the voice of the other. Within this shared life in understanding he argues, what is foreign becomes one's own and eradicates alterity and difference in the voice of another. Gadamer (1960/2004) argues that an authentically shared life is a shift from a singular perspective to a shared perspective: an encounter of joining perspectives. It is this shared life that creates participatory engagement with another and not just relation to another: not just sympathy to another but empathy towards one another. Adolescents with cancer occupy a shared life with each other. This conceptual framing resonates with my clinical practice with adolescents with cancer. As a clinician, I co-developed a monthly teen group for adolescents diagnosed with cancer. This group quickly became a community for those within it. I witnessed many moments of the enactment of this shared life: moments of adolescents occupying a community of a shared life.

I offer that many adolescents' implicit belief in a shared life with other adolescents diagnosed with cancer, facilitated their motivation and interest in participating in this research. Many adolescents reported that they thought it important to participate in this study. Curiously, many were unable to identify specific changes in their cancer experience to make the care more adolescent-centric yet, still wanted to participate to "*help other kids my age*". I offer again that this understanding of a shared life offers this motivation. Carl Jung (1951) writes about the wounded healer within the context of medicine: physicians who are wounded are compelled to heal others. In this perspective, adolescents diagnosed with cancer may be similarly compelled: their living with their own wounds inflicted from cancer compels them to want to respond to the

wounds of other adolescents diagnosed with cancer. Once wounded, they too want to heal others. Within this shared life, this shared understanding provokes them to want to respond to another.

### **Final Thoughts**

Situating this chapter within the phrase “far and near” responded to adolescents’ experiences feeling both far from, and close to, those around them following their diagnosis and treatment for cancer. My hope within this chapter was to widen how the relational experiences of adolescents throughout the cancer trajectory are considered and conceptualized. Similar to other ideas throughout this dissertation, I believe that adolescents’ relational connection to others has been narrowly explored in extant research on psychosocial impact from cancer. This research has often held the binary of impact or no impact and this chapter addresses both as co-occurring experiences for many adolescents. Clinically, we witness these shifts in adolescents’ connection with others, or perceptions of these changes in connection with others. I offer that the concepts discussed here facilitate a wider horizon of understanding these experiences.

## **Chapter Eight: Conclusion and Implications**

### **Introduction**

My goal within this dissertation has been to understand posttreatment in a different way: to acknowledge its inherent complexity and to deepen understanding of how this period of time is being lived by adolescents treated for cancer. Within this dissertation, I have outlined the current horizon of posttreatment. I have offered a review of literature that has been developed to investigate and understand a posttreatment period of time and how posttreatment might be experienced by adolescents and young adults diagnosed with cancer. I have also offered a conceptual review that has implicitly informed how the experiences of adolescents have been studied and understood within psychosocial oncology. Within these initial chapters, my intention has been to create an enlarged space to re-consider posttreatment from its traditional conceptualization.

The three chapters comprising my analysis are my interpretations of bringing more aspects of the topic of posttreatment into view: they are my response to the hermeneutic call of this topic. Hermeneutics opens up associations that strengthen understanding of a topic (Moules et al., 2015) and I believe that this approach has offered a deepened understanding of posttreatment experiences. After listening to adolescents sharing their experiences, writing and re-writing my interpretations, I am left with the strong belief that posttreatment is a diverse and complex time for adolescents. I also believe that the posttreatment experiences of adolescents and young adults are potentially distinct and that adolescents' needs and experiences are not always well understood within "AYA"-involved research. Although the tradition of posttreatment originates from trauma, distress, and psychosocial impact, this study confirms the demand to continue to enlarge aspects of this topic to be seen and understood.

Posttreatment as a topic constitutes a hermeneutical situation (Gadamer, 1960/2004): something to be interpreted and understood. Each of the topics in these chapters was a natural alignment to hermeneutics: each topic, both as a separate and as a whole, is deeply hermeneutic. Within each of these chapters, there were dominant threads of disorientation and displacement: in the body, in social structure, and within social connection. These were taken up individually within each of the chapters but they are threads that also weave together well within the larger topic of posttreatment. Within this final chapter, I first summarize these interpretive openings for understanding. I then discuss the implications of this study within methodology and psychosocial oncology care with adolescents. Finally, before concluding the dissertation, I discuss the limitations of the study.

### **Interpretive Openings**

I have argued throughout this dissertation that posttreatment has been narrowly examined. This research adds to the beginning scholarship on this period of time by offering a deeper understanding of posttreatment and how adolescents may experience it. Concepts and notions of posttreatment have largely been unquestioned and my work adds to the current research base that recognizes posttreatment as a diverse period of time for adolescents. This research also problematizes the dominant influence of distress in understanding posttreatment and suggests that the over-application of distress to AYAs' posttreatment experiences may not be the most valuable approach in understanding these experiences of adolescents. Surprisingly, very few adolescents I interviewed within this study talked about distress spontaneously and even when asked directly, spoke very little about distress experiences. Through the narratives and dialogues offered within this study, for many adolescents, distress did not constitute their primary experiences in posttreatment. Hermeneutics challenges the primacy

that is often accorded to dominant understandings of phenomena and my goal with this dissertation was to facilitate openings of this topic to be explored in ways outside of distress.

Chapter Five brings attention to the embodiment of cancer for adolescents. Many adolescents feel different in their bodies after a diagnosis and treatment for cancer. Many re-meet their bodies in a different way during posttreatment. I suggested throughout this chapter that cancer is embodied and for adolescents, this embodiment is brought into a clearer view during posttreatment. Further, I offer that posttreatment itself is embodied as many adolescents re-experience their bodies and may encounter a disruption in their physical biography during this period of time. How one lives in their body after treatment for cancer is an important part of the meaning adolescents make of their experiences.

Cancer is experienced through the body: the body is how cancer comes to be known. The body though has been neglected within inquiry involving adolescents with cancer. The body, so close to the attention of adolescents generally, holds significant meaning when the body changes and a different body comes into view following a diagnosis of cancer. The care of adolescents with cancer is informed by a disease-model and I have suggested that oncology care has relied on a Cartesian-reductionist view of the human body. As a clinician, I have neglected the body within my support of adolescents with cancer. I have attended to “cancer” and the experiences of being diagnosed with, and treated for, cancer. Yet I have failed to recognize that the body is how cancer comes to be both known and directly experienced for adolescents diagnosed with cancer. It is not “cancer” as a category but cancer as experienced by the body, that I think holds untapped understanding and meaning for adolescents diagnosed with cancer. Attending to cancer survivorship, and specifically posttreatment, is a call to re-consider the separation of mind and body in oncology practice and situate adolescents who have completed cancer treatment as

being-in-the-world in an embodied way. The body, as lived in by adolescents following the completion of cancer treatment, stresses the importance of attending to the embodied experiences of adolescents in the world after cancer treatment ends in efforts to understand this group of young people.

Chapter Six suggests that posttreatment is both a time of displacement and liminality for many adolescents. Cancer survivorship is predicated on a forward moving trajectory: a time of moving past a cancer diagnosis and treatment. Within this momentum, there is a desire for normalcy and a return to normal life which was shared by many adolescents. I offered within this chapter that a desire for normal was a desire for structure: a way to frame and position themselves following treatment. Adolescents may grieve the loss of structure that treatment provided. Posttreatment is often assumed anecdotally to be an invisible transition between treatment and surviving cancer. As a transitional space, this space has not been explored as a time of in-between and conceptualized as a space without structure. Considering posttreatment as a liminal space makes visible this invisible space where adolescents are caught between being a cancer patient and not being a cancer patient. This is significant as adolescents describe feeling in limbo between these two structures of meaning: they *often do not know where to go from there* (from cancer treatment). As clinicians, we often move adolescents to embrace and be excited about the restoration of normal life. The acknowledgement of a liminal space experienced after cancer treatment invites a necessary re-consideration of normal and how life might be after the completion of cancer treatment.

Finally, Chapter Seven explores adolescents' relational perceptions of closeness and distance from others during and following cancer treatment. Following a cancer diagnosis, the social relationships of adolescents have often been studied as a binary: the degree to which they

are impacted or not from a cancer diagnosis. This chapter explores adolescents' perceptions of feeling both close and far from others and offers interpretations of meanings within these social contexts. I offered the experience of companionship as a frame within which to understand these relationships throughout their treatment and posttreatment: adolescents feel both companioned and a loss of companions at different points within the cancer trajectory. In a following section of this chapter, I take up companionship again regarding recruitment within this study.

### **Methodological Implications**

The approach to method supported by Gadamer's philosophy of hermeneutics that I utilized within this research was a novel way to understand posttreatment experiences. As I have outlined within the previous literature review, psychosocial oncology research has addressed the topic of posttreatment from either the lens of quantitative measurement or as themed qualitative inquiry. Although both broad research approaches offer value into understanding this topic, they do not allow for the exploration of deep meaning that this approach of applied hermeneutics facilitates. The analytical insights that I have offered as interpretive openings within this research, would not have been generated without the ability to draw on Gadamer's (1960/2004) philosophical ideas of dialogue and language.

### **Dialogical Understanding**

The dialogical approach as suggested by the philosophical hermeneutics of Gadamer (1960/2004) and applied to a research context by Moules et al. (2015) offered me a different way to pursue understanding of the posttreatment experiences of adolescents. Firstly, the value of conceptual dialogue with the data allowed me to ask questions of the data and to have epistemological freedom to explore what I was seeing further. I was able to pursue the matter beyond the constraints of the linguistic word itself. Gadamer (1960/2004) writes about the

helplessness of the written word. In this perspective, the written word often becomes the repository of understanding however, understanding of the world emerges through our conversation with others. A dialogical approach to data, and dialogue as data, facilitated my entry into the play of this topic. In this way, dialogue represents this play: the back and forth movement of understanding. Entering into the play of this topic by way of dialogue allowed me to deepen my understanding of what I was reading in the transcripts as I could engage in dialogical questioning of the data. This facilitated an opportunity to preserve and consider the full horizon of a topic and to preserve its complexity rather than reducing it in efforts to understand.

This approach to dialogue also conceptualizes the voice of the data. In other words, voice within hermeneutic research is dialogical. Much of extant qualitative research in psychosocial oncology with adolescents has treated adolescent voice as pure representation of meaning that the researcher objectively hears and transcribes. This has resulted in research that seems to just skim the surface of the topic of inquiry. Feminist scholars have interrogated the use of voice as representative of meaning and argue that voices are contextual and do not represent stable meaning (McHugh, 2014). Attending to voice in qualitative research depends on how researchers hear these voices (Lather, 2007). Considering voice as dialogical removes the foci of voice from a participant. Rather, it represents the conversation within a research interview and voice is representation of this intentional dialogical exchange. In this perspective, voice does not pre-exist, and we are not “giving voice” to research participants. Rather, voice is a space where meaning is conceptualized and articulated. Adolescent voice as constituted by dialogue, removes the burden of soliciting voice from either participant and locates it within an interpreted, dialogical and relational space.

Within this dialogical context, dialoguing with the words that make up the data, offered me a novel way to engage with the data. Exploring the meaning of the words used in context allowed me to re-consider these words and to explore them within the context of this topic. This has reminded me of the living nature of language and that words are not stable representations. This engagement with words from the transcripts offered important and novel interpretations of how adolescents experience posttreatment and this richness of interpretation offered innovative meaning of aspects of posttreatment experiences. Specifically, “normal” and “alone” as I discussed Chapters 6-7 became portals to be opened and explored within the context of posttreatment. This inquiry into historical meaning of words, and not just an acceptance of how this meaning is currently expressed linguistically, facilitated new interpretations of this topic.

### **Dialogical Inquiry with Adolescents**

Regarding methodological considerations, I turn to considering the importance of a dialogical approach with adolescent research participants- especially within the conduct of research interviews. I was very present throughout the interview to the impact on participants of discussing their experiences of posttreatment. Many adolescents became upset at some point in the interview and required dialogue that deviated around the topic to enquire about these emotions and to ground them through their expressed emotions. One interaction which I will describe here illustrates the importance of approaching the research interview with adolescents dialogically and with presence and genuineness as Gadamer (1960/2004) described as necessary components of a true dialogue. During the interview, one participant cried openly and for frequent short intervals of time. I had to stop the interview a few times to check in with her about her emotions and to ask about her comfort in continuing the interview. She wanted to continue the interview but I did have to dialogue with her around her distress and comfort: some of these

questions were not related to my research topic and were not part of my interview protocol. This interaction suggested to me the value of dialogue when attuning to adolescent research participants. If I were rigid with my questions during the interview and did not allow the dialogue to follow the participant, I think she might have been harmed by this experience. Instead, I used dialogue to engage with her and to align with her throughout the interview.

Attention to these kinds of contexts is what Davies et al. (2020) highlight within their writing on conducting qualitative research with adolescents diagnosed with cancer. They draw attention to the ethical responsibilities of researchers conducting research with this population to consider the ways in which we engage participants and the conduct of these interviews. Guillemin and Gillam (2004) refer to these kinds of considerations as ‘ethically important moments’ that occur in the general practice of doing research. These are moments that manifest as ethical responsibilities of researchers to engage in ways that are present and mindfully attending to potential harms. Following the interview, she emailed me to express her beliefs that participating in this interview was a therapeutic experience for her and one that offered validation to her posttreatment experiences. This experience reminded me that all research has effects for participants and both researcher and participant come away from a hermeneutics-informed research interview, a dialogical interview, changed and with a different way to understand for this shared dialogical encounter.

Conducting the interviews with this group of young people was such a privilege: each shared a rawness of their experiences that surprisingly was easy to access. I was struck by the quick affirmative response offered by these adolescents who consented to be part of this study: they responded with a confirmation almost immediately into my telephone call with then regarding their consent. Consistently, within each meeting, the participants began sharing openly

as soon as the interview started: they almost seemed excited to participate. Many required few prompts: they began talking with me about their diagnosis, their treatment, and their posttreatment experiences. I felt that the interview provided an outlet to them, a formalized space, to discuss and share their thoughts and experiences. Many told me that they had not spoken about posttreatment with either their parents or their health care providers.

One adolescent in particular thanked me throughout the interview and sent me an email of thanks following. She found our conversation “better than a counselling session” even though I was intentional and self-reflexive to ensure that I was keeping the role clear for myself between her being a participant and not a client. I think that many adolescents during posttreatment may not openly share their experiences because there is not the space or permission to do so: there is no outlet. I also wondered how many adolescents may not be getting or accessing the support they need during this vulnerable period of time following the completion of treatment.

Listening to adolescents in these interviews reminded me of what I loved about clinical practice with this population: their humanness during pain and difficulty. I was struck with their clarity and the openness of their sharing. I found myself pulled in to their stories and charmed by their tellings of them. To me, this was the perfect context for self-understanding that Gadamer refers to. These interviews have changed how I think about these group of adolescents and I believe I am different in the world of practice with them: they continue to stay with me.

### **Psychosocial Practice Implications**

Hermeneutics-informed research often originates within worlds of practice. It is this situatedness in practice that often compels a response to understand the world of practice in a new way: to understand the problems we encounter in practice (McCaffrey & Moules, 2016). Although there is an inherent demand within a hermeneutic response to apply understanding to

practice, research conducted in the spirit of hermeneutics, does not easily translate to concrete guidelines and recommendations (Moules et al., 2015). I am reminded of the Greek concept of *techne* here. *Techne* is practical knowledge that has been developed to produce something specific: it is concrete and context-dependent (Gadamer, 1996). Hermeneutic research does not result in *techne*.

However, although not purporting to offer specific recommendations for practice, this research suggests implications for working clinically with adolescents following their treatment for cancer. Firstly, these findings support a more diversified understanding of posttreatment. My work supports posttreatment being a time with potentially diverse challenges and experiences for adolescents to confront. The breadth of participants' responses in this research opposes a dominant conceptualization of this period. I offer that considerations of the body, liminality, and social connection, are important topics to clinically attend to when working with adolescents who have completed treatment for cancer. Further, I hope this work is a preliminary step to better understanding the distress experienced by adolescents with cancer and may inform interventions to respond to, or mitigate, this distress. I believe that this research holds beginning implications for how posttreatment is theorized and understood clinically in oncology practice with adolescents.

Secondly, these findings suggest a more dynamic period of cancer survivorship more broadly. As I have previously outlined, cancer survivorship has become a general category of reference to clinically refer to the time following the end of treatment. There are a few studies that have recently referred to "posttreatment" within the trajectory of cancer survivorship as a distinct period of time. However, there remains little known about what living this period of time

might be like. The term “posttreatment” is not a formally established term or construct in current oncology practice.

Globally, models of cancer survivorship care are expanding rapidly and in the context of adolescents and young adults, there is increasing attention to improving the quality of survivorship care to this group of young people. The unique psychosocial and supportive care needs of this group of patients is beginning to be recognized and integrated within models of AYA cancer survivorship care. Although the focus within these programs has historical roots in biomedicine, primarily focusing on treating and managing disease and late-effects, increasing attention is being formally directed towards creating optimal service delivery for adolescents and young adults following treatment for cancer. However, these AYA survivorship programs do not address posttreatment as a time for distinct clinical attention (Baird et al., 2019; Burkart et al., 2018; Kinahan et al., 2015).

Finally, this research also calls for committing to understanding the experiences of adolescents—distinct from those of young adults. The time of adolescence is full of change, development, and transition. It is a time of strength, vulnerability, and uncertainty. Attention to the broader experiences of AYAs shadows these experiences of adolescents: experiences that I offer are potentially different from those of young adult and other aged groups within the cancer context. To best care for adolescent patients, there must be continued efforts to position their experience as the foci of inquiry.

I want to briefly return to the address of a topic and to being addressed: ideas of hermeneutics that I discussed in the introductory chapter of this dissertation. As stated, hermeneutic inquiry begins with an experience of being addressed by a topic (Gadamer, 1960/2004). When addressed, one is caught off guard but compelled to act and to join in its play.

The feeling of address offers a sense of being guided by the topic as opposed to a previous version of it (Moules et al., 2014; Moules et al., 2015). My work on this topic is my response to being addressed and to honouring the integrity of this topic as it became known to me within this research. This work has created an initial guiding thread for my work to come.

### **Study Limitations and Implication of Limitations**

Within this section, I discuss the limitations of this study. At the outset, it is important to highlight again that hermeneutics is an interpretive way of understanding. Therefore, the developed interpretations, the analyses, which I have offered in this dissertation are not representations of absolute truth: they are my interpretations. As I outlined in an earlier chapter, I have endeavored to offer rigorous and plausible interpretive accounts of adolescents' experiences. However, my interpretations are only possible interpretations: other researchers utilizing other methodologies may develop alternate interpretations. Although I am re-stating this approach to analysis here within this section on limitations, this is not an inherent limitation to this work. Topics of inquiry are complex and multi-faceted. Hermeneutics-informed research embraces understanding of different aspects of topics as a topic can never be fully known and understanding is never complete (Moules et al., 2015).

This research offers an in-depth focus on different aspects of adolescents' posttreatment experiences. Research within hermeneutics is not intended to be generalized: it endeavors to understand different aspects of a topic as lived out and experienced by different people. Within the small sample of this study, there was some demographic diversity but increased gender and racial diversity in the sample would have offered greater heterogeneity and may have led to different interpretations. Within this study, all participants identified as either male (70%) or female (30%) gender and only (23%) identified belonging to a racialized group different from

Caucasian. Although the sample is relatively small and localized, it offers a starting point in which to potentially build future research that continues to develop and widen understanding of posttreatment experiences. Diversity was also reduced by recruiting through a single institution. This may have limited diversity due to the inclusion of only one setting of cancer treatment.

Recruitment in this study was a limitation. Not the process of recruitment generally, but rather, who was chosen to be recruited. Within this study, I relied on recruitment efforts from pediatric oncology clinicians. Despite ongoing conversations about recruiting, recruitment was slow. However, what was more impactful, was that I believe that many clinicians unknowingly assessed adolescent compatibility with this study with some internal criteria to inform their decision to extend an invitation to an adolescent patient to participate in this study. Some clinicians reported that some adolescents were too “vulnerable” or “may get bad news soon” and so did not inform them of this study or offer an invitation for participation. This continued to occur despite my request to extend an invitation to participate to all adolescents who met the study criteria.

My interpretations within Chapter Seven regarding the companioning of clinicians with adolescents offers a lens to understand the decision-making practice that may have informed clinicians’ engagement with recruitment. Clinicians attend to adolescent patients diagnosed with cancer at the onset of the cancer diagnosis and care deeply about these patients. Within the hospital program within which my research occurred, I have witnessed a culture of genuine care and commitment to adolescent patients and their families following a diagnosis of cancer. The thread running through this dissertation is that adolescents are a unique group of cancer patients and that they have needs and experiences as cancer patients that are distinct because of their age and psychosocial development. The concept of companioning with adolescents by clinicians

suggests that oncology clinicians were potentially motivated to protect the adolescent and to have the adolescent patient avoid any potential distress experiences that they might experience through participation in this study. Many of the adolescents in this study identified as male (70%). Although this was a difficult detail to understand as it was emerging within the study, this lens of companioning offers some understanding. It is possible that boys were believed by recruiting clinicians to be less vulnerable, more robust, and to be experiencing less mental health symptoms as compared to adolescent females in treatment at the time of recruitment. It would be valuable to know, and a suggested gap of this research, is what informed clinicians' decisions regarding who they would recruit for this study.

Adolescents and young adults with cancer are expressing more direct statements of wanting to be involved within research directly and within the planning of research involving young people their age with cancer (Schilstra et al., 2021). A companioning stance is a valuable lens within which to understand the recruitment pattern in my study. However, it suggests a paternalism of authority that removes the autonomy of adolescents to decide, with their parents, if they wanted to participate in this research. Gadamer (1960/2004) writes that authority requires an active acknowledgement by others of the knowledge that one possesses. In this sense, authority is not blind obedience, but rather a decision to acknowledge another's knowledge. The authority of clinicians is privileged within the context of research recruitment: clinicians have knowledge of adolescent patients. However, I suggest that in order to advance adolescent-centric care, the authority of adolescents, the knowledge they possess as active agents, must be recognized within research activities; specifically, within recruitment. My research experience has highlighted to me the significance and value in understanding further how decisions are made to recruit adolescents for research within oncology settings. This is an important avenue

for future inquiry and could help to ensure greater numbers of adolescents have equal access to research participation.

Finally, I return again to my role in all aspects of this study and the necessary self-reflexivity involved within this engagement. As a clinician with this population and with developed practical knowledge, this background intersected with this work in likely both enhancing and constraining ways. This tension may have created limitations on this work as I drew from my particular clinical background and perspective while also imbuing this research with rigour and quality. Throughout this research, I have endeavored to keep a reflexive lens turned on myself in order to be aware of Gadamer's concept of prejudices and how they informed and constructed my thinking and interpretations. Throughout this research, I moved from what appeared evident in my understandings of the research problem, concepts and data, from an essentialized position of understanding of posttreatment experiences, to one that was hermeneutic and involved an ongoing, iterative process of self-reflexivity. In this way, my history as a clinician shaped both my original disposition to this research topic and informed the ongoing interpretations made throughout the research. I remain mindful that while I have tried to make the familiar 'strange' in my analytic approach throughout this dissertation, I am mindful that my efforts to think 'otherwise' are necessarily partial and incomplete.

### **Conclusion**

*It takes waaaay longer to recover from cancer than it takes to get through cancer.*

(Adolescent participant, age 15)

This dissertation offers different meanings of adolescents' experiences during posttreatment as they adapt to being thrown-in (Heidegger, 1927/2010) to posttreatment. In particular, this work offers alternate meanings of posttreatment as this period of time is lived by

adolescents. By illuminating the posttreatment experiences and the contextual conditions of posttreatment, my research vividly demonstrates that posttreatment as a phenomenon of study is diverse and dynamic. Mullan's (1985) words are borne out through this research: "survivorship should be studied as a phenomenon in itself rather than a byproduct or afterthought of basic research on cancer treatment" (p. 24). My research suggests that posttreatment has its own dimensions and qualities. It is neither treatment nor is it cancer survivorship: It is a space between with its own structure. Much more research is needed to better understand the lifeworlds of adolescents who complete treatment for cancer. In order to develop and improve programs and services focused on adolescents with cancer, it is vital to understand more comprehensively the contextual circumstances of their lives.

Within applied disciplines, we come to know the context of our practice. We develop expertise and wisdom that is beyond technical knowledge (*techne*) and skill development. We begin to embody our practice. Aristotle used the term *phronesis* to refer to a type of wisdom, or deep understanding of a phenomena that has developed from practical engagement with a topic (Moules et al., 2015). This is different from technical knowledge which can be learned and forgotten. In *phronetic* knowledge, this practice wisdom becomes how we are within the world of practice.

Hermeneutics responds to a desire to understand the world differently. In applied disciplines, hermeneutics is a call to understand practice differently. The impetus for interpretation comes out of practice: something in practice has addressed us that requires our attention. Within a research context, interpretations are oriented on the phenomenological experiences of people who comprise our practice. Gadamer (1960/2004) used the term "self-understanding" to convey the change that hermeneutic understanding facilitates. This self-

understanding is not understanding of the self per se but rather, his belief that this new understanding becomes part of a person's thinking. This leaves the interpreter changed and in the context of practice disciplines, changes us within these contexts.

Hermeneutics strives to understand the problems we confront within the worlds of practice. It brings a different kind of understanding to human action in the world- and in this context, to phenomena we confront in our practice with people (Moules et al., 2011). Gadamer believed that application is essential to the hermeneutic process of understanding. Our engagement with the world is practical and as we arrive at a different understanding of a topic, we engage with this topic in the world of practice in a different way (Moules et al., 2015). Hermeneutics pulls a topic from the abstract to the concrete and this brings us closer to the lived experience of illness and health. Benner (1994) discussed that the understanding acquired in interpretive inquiry is key to “becoming more effectively, skilfully, or humanely engaged in practice” (p. xv). Hermeneutics offers the opportunity to engage in more thoughtful practice and to apply a different understanding of a topic that lives so intimately within the lives of the people who are in the contexts we study.

This research has changed my perception of this topic and has changed me as both a researcher and clinician committed to caring for adolescents diagnosed with cancer. I would like to close by again returning to my clinical practice with adolescents with cancer. One adolescent I cared for had been a patient for many years: she was diagnosed with aggressive leukemia, had a bone marrow transplant, developed graft vs host disease (GVHD), experienced significant physical side-effects from the treatment for GVHD, among numerous other cancer-related reasons that led to significant periods of time admitted to hospital. I came to know this adolescent very well and saw her almost weekly for years. She was strong, direct, emotionally

labile, and was very attached to me. When I had decided to leave my clinical practice and pursue doctoral training, I was very nervous about how to tell her I was leaving my clinical position: I expected some anger, frustration, and her projected fear of being abandoned. As I began to tell her what led to this decision- being addressed by the topic of posttreatment experiences and my helplessness as a clinician witnessing these experiences, she burst into tears and said: *Thank you for helping people like me! Can I use my Make-a-Wish to pay for your PhD?* I think what is truly at play here is the quality of the lives lived by adolescents following their treatment for cancer. I hope my work on posttreatment contributes to more comprehensively understanding them.

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## Appendix A



**a place of mind**

**THE UNIVERSITY OF BRITISH COLUMBIA**

**Adolescent Information and Assent Form**

Cancer as interruption: Exploring the experiences of adolescents who have recently completed treatment for cancer

**WHO IS IN CHARGE OF THE STUDY?**

**Principal Investigators:**

Dr. Paul Rogers, MD  
Division of Hematology and Oncology; Department of Pediatrics  
B.C. Children's Hospital

Dr. Grant Charles, PhD, RSW  
School of Social Work  
University of British Columbia

**Co-Investigator:**

Andrea Johnson, PhD(c), RSW  
PhD Candidate  
University of British Columbia

The principal investigator of this study is Dr. Paul Rogers. He is being helped by Dr. Grant Charles and Andrea Johnson. This study is the PhD dissertation study of Andrea Johnson. They will answer any questions I may have about the study. I am aware that I am welcome to contact them at the numbers listed above.

**INVITATION**

I am being invited to take part in this research study because I have been previously diagnosed with cancer and I have recently completed treatment for cancer. This study will include approximately 20 adolescents as participants. Each adolescent who is between ages 13-19 and who has completed treatment for cancer at BC Children's Hospital is invited to participate in this study.

The following pages explain the study so that I can decide if I want to take part or not. I should take time to read the following information carefully and talk it over with my family and the researchers above before I decide to participate.

**DO I HAVE TO BE IN THIS STUDY?**

I do not have to participate in this study if I don't want to. It is up to me if I want to be in this study. No one will make me take part in this study and no-one will get upset with me if I don't want to participate in this study. I do not need to provide any reason why I have decided not to participate.

If I want to participate in this study, I will be asked to sign this form. My parent/guardian will also need to sign a consent form before I am enrolled in the study; but I do not have to participate even if they sign the consent form. The researchers will not enroll me into the study unless I agree to do so. I understand that I should feel free to talk to the study researchers if something is not clear. I can choose to be in the study, not be in the study, or take more time to decide. Even if I agree now to be part of the study, I can change my mind later. I can stop being a participant in the study at any time. Whatever I decide, my medical care will not be impacted by my decision to participate in this study.

### **WHY ARE WE DOING THIS STUDY?**

Many adolescents are diagnosed and treated at BC Children's Hospital. We know that having cancer as an adolescent is a different experience than being diagnosed with cancer as a child or an adult. We have a lot to learn about what cancer is like for people your age. This study specifically is trying to understand what finishing treatment is like for you. We use the term 'posttreatment' to refer to the period of time after active treatment ends. We are curious about what posttreatment is like for people your age and this will help us better support adolescent patients once they have finished treatment for cancer.

### **WHY AM I INVITED TO BE IN THIS STUDY?**

I am being invited to be in this study as I have completed treatment for cancer 0-18 months ago. This study will explore what finishing treatment is like for me.

### **WHAT WILL HAPPEN TO ME IN THIS STUDY?**

If I choose to participate in this study, I will meet with the co-investigator of this study, Andrea Johnson, for an interview. This interview will last approximately one hour. The interview will occur wherever is convenient for me- in the oncology clinic or in my home. If I would prefer the interview to happen at my home, the research team will ensure that my parent is also at home. I will be asked questions about my thoughts and feelings about finishing treatment for cancer. These questions have been developed to help the study team better understand what finishing treatment for cancer is like for people my age. I do not have to answer each question. If there is a question that I do not want to answer, I can let Andrea know and I won't have to answer it. If I agree (assent), this interview will be recorded. This will allow the study team to listen to the interview again. There is also a short survey for you to complete. This information will help the research team when analyzing everyone's data. Studies involving people with cancer now routinely collect information on such characteristics as age, ethnicity, gender, time-line of treatment because these characteristics may influence how someone experiences their cancer diagnosis and treatment. It is completely voluntary if you want to provide this information. At the end of the study, I will be asked if I would like to be contacted again with the findings of this study. I will be asked for my consent to be contacted after the end of the study interview.

### **CAN ANYTHING BAD HAPPEN?**

The interview questions do not involve sensitive questions specifically but I may experience different emotions when answering them. I understand that if any emotion feels too difficult, the interview can be stopped. I am also aware that I don't need to answer every question if a question feels too difficult to answer. If talking about finishing treatment for cancer makes me feel upset, I will let the researcher know who is interviewing me. She will talk with me about how I am feeling and she will connect me to a psychologist at BC Children's Hospital if I want

to talk to someone about how I am feeling. If I continue to experience emotions or thoughts that make me upset, I can tell my oncologist and oncology nurse clinician. I also know that I can contact the researchers of this study. I may be having some thoughts or emotions after the interview and I may want to talk to someone about them. At the start of the interview, I will be given the contact information for the psychologists in the pediatric oncology program at BC Children's Hospital and as well as some contacts of counsellors in the community. I am aware that I can contact them if I need to.

### **WHAT ARE THE GOOD THINGS ABOUT BEING IN THIS STUDY?**

There are no direct benefits to you from participating in this study. However, there may be indirect benefits. One possible indirect benefit from participating in this study is to help raise awareness of the experiences of adolescents who have completed treatment for cancer. This study may help doctors, nurses, and other healthcare professionals in oncology learn more about adolescent cancer survivorship and therefore better understand the unique experiences of adolescents after they have completed cancer treatment. There is a lot that oncology clinicians do not know about your experiences after you have completed treatment. This study hopes to widen this understanding. When oncology clinicians better understand the experiences of adolescents like you, this may change their practice to support and understand adolescents diagnosed with cancer in a different way.

### **WHO WILL KNOW I AM IN THE STUDY?**

My privacy will be respected. Unless I allow them to, the study team will not tell anybody else who I am or if I have been a part of this study. My parents will not be told about what I discuss in the interview. However, if during the interview, I discuss that I feel like harming myself or someone else, my parents and my doctors (and other appropriate health and security professionals) will be contacted by Andrea (the co-investigator who will be conducting the interview) and told this information. The research team is legally required to tell people if they are concerned about my safety or the safety of someone else.

The research team will not release any other information to anybody else that could be used to identify me. In order to protect my privacy, the study team will remove any information that may be used to identify me from any study documents, and instead of my name appearing on them, I will be identified by a specific study code number that applies only to me. This code number will not be shared outside of the study team and only this code number will be used on any research-related information collected about me for this study, so that my identity as part of the study will be kept completely private. Only Andrea Johnson the co-investigator of this study will have the ability to link this code number with my personal information, and the linking information will be kept in a locked cabinet in Dr. Charles' office in the School of Social Work at UBC under the supervision and control of Dr. Charles. All audio recordings, interview notes, and interview transcriptions will be identified with my code number and will be kept in this locked filing cabinet. Audio recordings will be destroyed after your interview has been transcribed. Copies of questionnaires and transcripts will be shredded 5 years after the study is complete.

If I choose to withdraw from the study, the interview information collected will be destroyed.

### **WHAT WILL THE STUDY COST ME?**

There is no cost for me to participate in this study. I will not be paid for participating in this study. If I have to pay for parking at the time of the interview of this study, this cost for parking will be reimbursed to me or to my parent.

### **WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?**

If I have any questions or desire further information about this study before or during participation, I can contact this study's co-investigator (Andrea Johnson) or the principal investigators on page 1 of this document.

**WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT DURING THE STUDY?**

If I have any concerns or complaints about my rights as a research participant and/or my experiences while participating in this study, I should contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics.

**FUTURE STUDIES**

There is a chance that during or after this study the study team will find other questions needing answers that require future studies. If I am willing to hear about these future studies, I will make the “yes” box. This does not mean that I will have to take part in a new study, just that the study team will let me know about it. If I do not want to be contacted about new studies, I will mark the “no” box.

*Are you willing to be contacted by the researchers for future studies?*

- YES**
- NO**

***ASSENT TO PARTICIPATE IN RESEARCH***

My signature below indicates that I have read and understood the information in this document and that I have decided to participate based on the information provided.

- I have read and understood this information and assent form.
- I have had sufficient time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had satisfactory response to my questions.
- I understand that all of the information collected will be kept confidential.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or withdraw from this study at any time without changing in any way the equality of care I receive.
- I understand that I can continue to ask questions, at any time, regarding my participation in this study.
- I understand that if I put my name at the bottom of this form, it means that I agree to be in this study.

I will receive a signed copy of this assent form for my own records.

I agree to participate in this study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

## Appendix B



**a place of mind**

**THE UNIVERSITY OF BRITISH COLUMBIA**

### Parent Consent Form

Cancer as interruption: Exploring the experiences of adolescents who have recently completed treatment for cancer

**Principal Investigators:** Dr. Paul Rogers, MD  
Division of Hematology and Oncology; Department of Pediatrics  
B.C. Children's Hospital

Dr. Grant Charles, PhD, RSW  
School of Social Work / Adolescent Health & Medicine  
University of British Columbia

**Co-Investigator:** Andrea Johnson, PhD(c), RSW  
PhD Candidate  
University of British Columbia

### INTRODUCTION

Throughout this consent form, "you" refers to your child as a participant in this research study.

Your child is being invited to be a participant in this research because she or he has recently completed treatment for cancer. This study will include approximately 20 adolescents as participants. Each adolescent who is between ages 13-19 and who has completed treatment for cancer at BC Children's Hospital is invited to participate in this study. This study is the PhD dissertation study of the co-investigator, Andrea Johnson.

### PARTICIPATION IS VOLUNTARY

Your child's participation is entirely voluntary, so it is up to you and your child to decide whether or not your child will participate in this research study. Before you decide, it is important for you and your child to understand what this research study involves. This consent form will tell you about the study, why the research is being done, what will happen to your child during the study and the possible benefits, risks and discomforts.

If you wish your child to participate, you will be asked to sign this form. Your child will also be asked to sign a participant assent form. If you and your child do decide to take part in this study, you, and your child, are still free to withdraw at any time and without giving any reasons for your decision.

If you do not wish your child to participate, you do not have to provide any reason for this decision. Your child will not lose the benefit of any medical care to which your she or he is entitled to or is currently receiving. Please take time to read the following information carefully before you decide whether to participate in the research.

### **WHAT IS THE PURPOSE OF THE STUDY?**

This study is being conducted to explore the experiences of adolescents who have recently completed treatment for cancer. There is a limited amount of research done specifically with adolescents during the time after they have completed treatment for cancer and there remains much to know about what this period of time is like for them. The purpose of this study is to increase what we know about the experiences of adolescents following completion of treatment for cancer. We intend for this understanding to impact our care of patients in this age-group.

### **STUDY PROCEDURES:**

If you consent for your child to participate in this study, your child will have one interview with Andrea Johnson, the co-investigator of this study. Each interview will last approximately one hour. Interview questions have been developed to specifically ask about the experiences after someone has completed treatment for cancer. The interview will be scheduled at a time that is convenient for you and your child. The interview will likely occur in the oncology clinic at BC Children's Hospital. If you and your child would prefer the interview to occur at your home, the research team will ensure that you are present in the home at this time. Your child will be asked if she/he would like you to be present for the interview. If you consent, this interview will be audio recorded and transcribed. There is also a short survey for your child to complete. This information will help to inform the analysis phase of this study. Studies involving people with cancer now routinely collect information on such characteristics as age, ethnicity, gender, time-line of treatment because these characteristics may influence how someone experiences their cancer diagnosis and treatment. Your child providing information on these characteristics is voluntary. At the end of the study, your child will be asked if she/he would like to be contacted again with the findings of this study. Your child will be asked her/his consent to be contacted again after the end of the study interview.

### **POTENTIAL RISKS:**

Interviews may contain questions that evoke emotion. None of the developed questions are specifically emotionally sensitive in nature, however, in answering them, emotions may arise. Andrea Johnson is clinically trained to support adolescents and has extensive experience interviewing and supporting adolescents. If, following participation, your child continues to experience a difficult emotion, a referral for further support will be discussed with your child and yourself and then made. If your child experiences any difficult emotions throughout the interview, your child will be asked if they would like to stop the interview. Prior to the start of the interview, your child will be provided with list of contacts for further counselling support. This list includes the contacts of the psychologists in the pediatric oncology program at BC Children's Hospital as well as community contacts for counselling support for your child.

### **POTENTIAL BENEFITS:**

Participants may or may not benefit from participating in this research. The benefits of participating in this research could include discussing what a certain period of time is like for her or him. We know that many

adolescents have never been asked about their posttreatment experiences from cancer. Another benefit might be to raise awareness of the experiences of adolescents who have completed treatment for cancer. We hope that this study will help clinicians in oncology to learn more about cancer survivorship and adolescents and better understand the unique experiences of adolescents after they have completed cancer treatment.

### **CONFIDENTIALITY:**

Each research participant's identity will be kept strictly confidential. Your child's confidentiality will be respected and the research team will not be able to share the content of your child's interview information with you. However, confidentiality will be broken if your child discloses any thoughts of harming her/himself or harming someone else. This information will be shared with you and the appropriate health and security professionals as appropriate. The research team is under legal obligation to break confidentiality in cases when an adolescent's safety or safety of another is at risk. Research records and health or other source records identifying your child may be inspected in the presence of the Investigator or his or her designate by representatives of UBC Children and Women's Hospital Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your child's identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law. All interview transcriptions, interview notes, and audio recordings will be identified only by code number and kept in a locked filing cabinet in one of the Principal Investigator's research lab at UBC. All computer files containing data records will be password protected. Only the research team will have access to your surveys and interview transcripts. Participants will not be identified by name in any reports of the completed study. Audio recordings will be assigned identification numbers to protect your child's identity. Audio recordings will be destroyed after your interview has been transcribed. Copies of transcripts will be shredded 5 years after the study is complete.

All efforts will be made to protect your child's confidentiality. However, in the event of an unexpected data breach, it is possible that your child's voice could be identified from the audio recording. However, audio recordings will be securely stored as noted above and only accessible by the research team of this study.

### **CONTACT FOR INFORMATION ABOUT THE STUDY:**

If you have any questions or desire further information with respect to this study, you may contact Andrea Johnson (Co-Investigator).

### **CONTACT FOR CONCERNS ABOUT THE RIGHTS OF RESEARCH PARTICIPANTS:**

If you have any concerns about your treatment or rights as a research participant, you may contact the Research Participant Complaint Line in the UBC Office of Research Ethics.

### **WITHDRAWAL:**

Your child's participation in this research is entirely voluntary. Your child may withdraw from this study at any time, and without giving any reasons for her or his decision. If your child decides to enter the study and to withdraw any time in the future, there will be no penalty or loss of benefits to your child which your child is otherwise entitled, and your child's future medical care will not be affected. If your child decides to withdraw,

the data she/he has provided will be destroyed. All paper documents made related to your child's participation in this study will be shredded and the audio recording of the interview will be erased.

### **FUTURE STUDIES**

There is a chance that during or after this study the study team will find other questions needing answers that require future studies. If I am willing for my child to hear about these future studies, I will make the "yes" box. This does not mean that my child will have to take part in a new study, just that the study team will let my child know about it. If I do not want my child to be contacted about new studies, I will mark the "no" box.

*Are you willing to be contacted by the researchers for future studies?*

- YES**
- NO**

## **PARTICIPANT CONSENT FORM**

### **KEEP THIS PORTION FOR YOUR RECORDS**

I understand that my child's participation in the above study is entirely voluntary, and that I, or my child, may refuse to participate. In addition, I or my child is free to withdraw from the study at any time without jeopardy to health care services.

If I or my child withdraws from the study, I understand that I can request the data be withdrawn prior to analysis or publication. The data will be destroyed.

I have received a copy of this consent form for my own records. I consent to my child's participation in this study and in signing this document I am, in no way, waiving the legal rights of myself or my child.

I have kept copies of both the letter describing the study and this permission slip.

The parent(s)/ guardian(s)/ substitute decision-maker (legally authorized representative) and the investigator are satisfied that the information contained in this consent form was explained to the adolescent/ participant to the extent that he/she is able to understand it, that all questions have been answered, and the adolescent/participant assents to participating in the research.

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*Parent's Signature*

---

*Printed Name*

---

*Date*

---

*Son or Daughter's Name*

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Researcher obtaining consent

## Appendix C

**a place of mind****THE UNIVERSITY OF BRITISH COLUMBIA****RESEARCH STUDY INFORMATION****Cancer as interruption: Exploring the experiences of adolescents who have recently completed treatment for cancer**

We are inviting you/your child to participate in a research study called- **Cancer as interruption: Exploring the experiences of adolescents who have recently completed treatment for cancer**. The principal investigator is Dr. Paul Rogers, MD. The co-investigator is Andrea Johnson, PhD(c) (The School of Social Work, UBC).

**YOUR PARTICIPATION IS VOLUNTARY**

You/your child's participation in this study is entirely voluntary so it is your decision to consent to participate in this study. Please take time to read the accompanying consent/assent forms. If you do not wish to participate in this study, you do not have to provide any reason nor will this decision have any consequence or impact to the medical care you receive at BC Children's Hospital. If you would prefer not to be contacted again about this study, please do let the nurse or child life specialist who has approached you about this study know.

**What is the purpose of the study?**

We hope to improve the understanding of the experiences of adolescents who have completed treatment for cancer. The posttreatment period of time is under-studied and we don't have enough information to help us best support adolescents who have recently finished cancer treatment. We hope that information from this study will enhance our care of this age group as cancer survivors. This will help us plan programming and supports for this age-group of patients diagnosed with cancer.

**Study Outline:**

If you/your child decide to participate in this study, you/your child will be invited to take part in an interview that will last approximately 60 minutes. This interview will be a series of questions that will ask about posttreatment experiences from cancer. This interview will be audio recorded.

**Contact Information:**

If you would like to participate in this study or have any questions about your participation, please contact Andrea Johnson.

Thank you for considering participating in this study.

## Appendix D

### Interview Guide

**Preface:** *“This interview is about the experiences of people your age who have finished treatment for cancer. This study has been designed to help us learn more about what finishing cancer treatment is like for people your age. This interview will take about an hour and I will be asking you questions about being diagnosed with cancer and finishing treatment. These questions are not yes and no questions but questions that have been created to encourage you to discuss your answer. You do not need to answer all of the questions. Your participation is confidential. While I will use what you tell me in my study I won’t attach your name to anything that I write down about this interview. Should you wish to stop at any point, please let me know and we will stop this interview immediately. Do you have any questions?”*

**Diagnosis/Treatment:**

1. Can you tell me what life was like for you before being diagnosed with cancer? What was life for you after your diagnosis?

**Probes: (if needed)**

What did you know about cancer prior to your diagnosis? Was getting sick something you imagined could happen?

What was it like for you to hear you had cancer?

What was it like for you to receive treatment?

**Posttreatment:**

Prompt: *I want to remind you that you are free to not answer any question or to come back to a question later if you so choose or to stop the interview at any time. Just please let me know. These next questions ask about how aspects of your life might have changed since you were diagnosed with cancer.*

1. What has life been like for you since you finished your treatment? (friends, family, school, dating etc.).

**Probes: (if needed)**

What has school been like for you since you have finished treatment? What was it like to be at school during treatment?

What kind of social activities are you engaged in now? Has this changed from before you had cancer? Or when you were in treatment? If so, how?

What are your relationships with your friends like now? Has this changed from before you had cancer? Or when you were in treatment? If so, how? Has there been any big changes in your relationships with your friends?

How did your family respond to you during the time you were diagnosed with cancer and receiving treatment? How did they respond after treatment ended? What are things like in

your family now that you have finished treatment? Has there been any big changes in your relationships with your family?

Are you dating? Has this changed since having cancer? Has this changed from before you had cancer? Or when you were in treatment? If so, how?

Are you sexually active? Has this changed from before you had cancer? Or when you were in treatment? If so, how?

Any other aspects of your life that we didn't yet talk about that have been changed by cancer?

2. What did you think finishing treatment was going to be like? What did people tell you?
3. What do you think is the most difficult part about finishing treatment and surviving cancer? Why do you feel that way? How about the most surprising part? Why do you feel that way?
4. Do you have fears or worries that you didn't have prior to your diagnosis or treatment? For example, do you have fears about getting sick again, your mortality, sexuality, fertility, or feeling different from other people? If you do have any fears, what sort of impact are they having on your life?
5. Are there other things in your life that are different or feel different now compared to before you were diagnosed or when you were in treatment? Any things that haven't changed?
6. What makes a good day for you? What makes a bad day for you now?
7. What do you think of when you hear the terms cancer survivor and cancer survivorship?
8. If another person your age was at the end of their cancer treatment, what do you think is important for her or him to know? Why? What do you wish you knew?

**Future:**

1. What are your thoughts about the future? What did you hope for prior to cancer? What do you hope for now?
2. What do you think your life would be like if you didn't get cancer?

**Conclusion:**

1. If there was one really important take away from our conversation today that you wanted me to remember, what would it be?

*Thank you for your willingness to talk to me and taking part in this study. As I said when we started, while I will use what you tell me in this study, I won't attach your name to anything that I wrote down about this interview. Is there anything you said to me that you wouldn't want me to use in the study keeping in mind that no-one will know it was you who said anything?*

2. Is there anything else that you would like to tell me?
3. Do you need me to arrange some support for you as a result of our discussion?

## Appendix E

**a place of mind****THE UNIVERSITY OF BRITISH COLUMBIA****Demographics Information Form**

Cancer as interruption: Exploring the experiences of adolescents who have recently completed treatment for cancer

Please provide the following information. You do not have to complete this form or answer any questions that you do not feel comfortable answering. Not providing information on this form does not mean that you can't take part in this research study.

Participant ID:

1. Age
2. Self-identified Gender
3. Grade
4. Self-identified ethnicity
5. Number of Siblings
6. Family Composition (who is in your family?)
7. Born in Canada? (yes or no)
8. Do you live in an urban or rural community?
9. Diagnosis
10. Age at diagnosis
11. Month/year that treatment started
12. Month/year that treatment ended
13. Your age when you finished treatment