

CRITICAL MOMENTS OF MEANING AND BEING:
NARRATIVES OF CANCER DURING YOUNG ADULT LIFE

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ABSTRACT

Emerging conversations within oncology have drawn more attention to cancer among young adults (ages 18-45). Recent research has illuminated many of the psychosocial difficulties young adults face as they go through the many trials and tribulations of chronic illness. However, a subject still understudied, much is unclear about the personal as well as the cultural implications of being diagnosed during this period of time. In a book of cancer stories, performer and young adult cancer patient Kairol Rosenthal (2009) expressed her frustration with what she saw as “stereotypes” promulgated by the limited public discourses that exist on the subject (p. 7). She sought to counterbalance these representations with stories capturing the “complexities of our real daily lives” (p. 7).

Indeed, in oncological discourses young adults tend to be cast in oversimplified terms, based upon cultural expectations about what young adulthood should be and pressures to conform to those standards. Intersecting with dominant discourses within narrative identity development, two imperatives are placed upon young adults’ stories: integration of different life experiences and selves into a coherent narrative and developing a sense of self-authorship in the direction of one’s life. What seems to be lost in these imperatives within the existing research is what is at stake for individual lives (a phenomenological perspective) and how those stakes are negotiated or contested with hegemonic trajectories of life (a critical perspective).

Receptive to Rosenthal’s critique of dominant discourses around cancer and young adulthood, the purpose of this thesis was to explore the complexity and diversity of young adults living with cancer. More specifically, I intended to interrogate some of their existential and biographical challenges as expressed in their narratives of cancer, as well as their engagements with ideological constructions of young adulthood, namely, the expectations of narrative

coherence and self-authorship. This research marked a departure from most studies on the subject in its qualitative methodology (i.e., narrative analysis) and in its explicit evaluation of the effects of cultural discourses on young adults' attempts to make meaning. More generally, this research shows the importance of language—in discourses, narratives, and metaphors—in constructing and communicating illness experiences.

For this project, I gathered a mix of written and oral narratives (through semi-structured interviews) from 21 participants from across Canada. The foci of analyses were on what could be called narrative 'moments of meaning' and 'moments of being,' that is, situated expressions of how they made sense of their worlds and themselves. Many of these were critical moments in the sense of questioning and resisting dominant discourses of cancer and young adulthood. Their moments of meaning often expressed negotiation of personal desires and innovative intentions with familiar cultural narratives or "prototypical plots" (Good, 1994)—including stories of battling cancer, embarking on a life journey, nearing recovery, encountering unpredictability and mystery, and living with chaos. These moments of meaning served an array of purposes well beyond the expected function of constructing a coherent narrative.

When telling of identity disruptions and the liminality of cancer, participants produced both more orderly moments of being (e.g., survivor, patient, or warrior identities) and more liminal moments of non-being (e.g., victim, phoenix, or trickster identities). Self-authorship seemed to be present among the former, while the latter expressed less control and certainty of being—which was not always seen as a problem. These moments of being and non-being were collaborated and contested within the intersubjective spaces of their clinical relationships, local worlds, and cancer patient communities. More specific to their age group, their moments of being and non-being often related to what may be understood as developmental identities,

including the ‘traditional milestones’ such as individual autonomy, family (i.e., marriage and parenthood), and vocation (i.e., getting an education and building a career). In their struggles they sometimes reaffirmed these cultural ideals toward identity integration and other times resisted them as “normalizing ideologies” (Becker, 1997) of young adulthood.

As part of these larger negotiations of meaning and being, the participants expressed struggles to understand the moral significance of their illnesses. Confronted with what may be called “causal ontologies” of suffering (Shweder, 1997), they spoke of different etiological models of cancer’s origins as well as reconciliatory models for living with cancer in the future. Their narratives sometimes led toward “remoralization” (Kleinman, 1988)—couching experiences of suffering in terms of a moral order (narrative coherence) and personal responsibility (self-authorship)—and sometimes led away from it, depending on whether they believed their illnesses originated from events in their personal and social lives.

Overall, the participants in this study communicated complex and potentially chronic existential challenges. In many ways their narratives resisted dominant representations of young adults with cancer—and of cancer patients in general—suggesting that such representations need to be rethought. Their critical moments of meaning and being may serve as counternarratives to the stereotypes of concern to Rosenthal and many other cancer patients. Specifically, their narratives revealed the merits and limits of the ideological construction of young adulthood as a time of narrative coherence and self-authorship. This study has important implications for future health research and psychosocial support in the field of oncology; building upon a “narrative medicine” (Charon, 2006), sensitivity to how language is used among young adult cancer patients may lead toward more inclusive clinical practices.

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To begin with, Dr. Teucher's and my life have been entwined for over six years now. Our relationship began while I was an undergraduate student in need of an Honour's project. At our first meeting he instilled in me a passion and love for health research that has miraculously carried me over the obstacles of time to this point, where it now seems impossible to roll back or even stall that fervor. His insistence upon maintaining compassion and due consideration has created a monster of sensitive and meticulous self-doubt, and I do not know if I will be able to thank him enough.

I had another partner who also oversaw my labours and provided nourishing encouragement where my will to continue had all but died. My wife, Brianna Hammond, lovingly tolerated my hermit-like behaviours during the most demanding days of graduate studies. Aesthetically observant, she polished my shoddy writing and my presentation style when I hadn't yet realized that both are forms of art. In recent days, she for the most part went solo in caring for our baby boy Baron while I wrote the final pages of this chapter in our lives. I suspect my sanity and my work ethic would be long gone by now without Brianna's continual guidance along the way.

My committee was the life-saving anchor to my floating whims and ambitions. They received what must have appeared to be unattainable and absurd proposals with remarkable patience and understanding. Leslie Howe collaborated with my attempts to integrate philosophy and psychology, and rightfully told me to go back to my Sartre. Phil Carverhill supported me in two capacities, as committee member and instructor for volunteer training for the Prairie Hospice, and in both helped me to navigate the difficult terrain of death and dying. I leaned upon Linda McMullen, who also instructed me at one point, to get my bearings of qualitative research before I got lost in a pit of competing methodologies.

The Qualitative Research Centre provided me with privileged access to essential equipment and services for carrying out my project. Co-founded by my supervisor, the Centre offered a convenient space for holding conversations and meetings, writing until my wit's end, and drinking an endless supply of tea. There was, of course, the coordinator of the QRC, Laurie Schimpf, who for all intents and purposes served simultaneously as motherly and disciplinary figure. Words rushed onto the page at her insistence to "hurry hard," coupled with an application on her phone that made a whipping sound. A philanthropist of ideas, she seemed to carry an endless supply of creative and ingenious suggestions she shared freely and without expectations of reciprocity.

Finally, I am deeply indebted to each and every member of the Cancer and Young Adulthood team for having developed a collegial and informal atmosphere for sharing thoughts and perspectives. I cannot praise them enough for their many valuable conversations over how to read individual narratives and for their critical feedback on some of the material presented within this dissertation. I may owe them a cake for this.

DEDICATION

The deaths of the past birth the lives of the future.
Witnessing the passing of those dear to me has ignited,
not diminished, my desire to work with those in crisis.

I carry my personal flame for Jack Morrell, Josie and
Mark Hammond, William Acker, Leona Altermatt,
and many others whose powers have surpassed their lives.

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Young Adult Cancer

“Survivorship stories [have] created a stereotype of cancer patients...I aspired to rip young adult cancer patients from the confines of these limited descriptors and perceptions...I wanted to reveal who we are, not in simple definitions but in the complexities of our real daily lives”

—Kairol Rosenthal, *Everything changes*, p. 7

Introduction

The stage was set for actor, director, and former cancer patient Kairol Rosenthal’s interview project on young adult cancer. Through directed attacks at prevailing assumptions about survivors—their inherent strength of character, enhanced awareness of moral living, and humbling wisdom about the meaning of life—she endeavoured to break down the hardened caricatures of younger cancer patients as imagined within popular discourses. With so many spirited, ribbon-waving efforts to generate more awareness of cancer, Rosenthal believed what was needed most was a few accenting threads to add more colour to the fabric of public perceptions. The best way to do this, she concluded, was to gather and publish stories of cancer.

Rosenthal’s (2009) subsequent book on young adult cancer is for me both an enduring source of inspiration and a sobering memento. It is a stinging slap to the face, jerking me out of a comfortable reverie wherein I dream I can know the totality of illness experience. Her book challenged me in my research to question dominant discourses around cancer and young adulthood, under which I am influenced as well, by showing how they oversimplify life in transition.

Yet, I did not want to deny the sway these discourses have in the lives of young adults with cancer; as Rosenthal noted, these “limited descriptions” of cancer patients often come out of

patients' own stories of survivorship. There is no clear-cut distinction between popular images and self-images of people living with cancer, who may integrate, defuse, and/or manipulate discourses as they tell their stories of illness. Like Rosenthal, I sought to understand young adult life in its complexities and nuances, while attending to shared meanings, stories, and identities between people of differing diagnoses, treatments, and challenges.

The title of Rosenthal's book helps us to imagine just how profoundly the onset of cancer can transform people's lives; I tried in my research to work out what 'everything' meant for each person. One way to get at 'everything' is to ask the question, 'What is at stake here?,' a line of enquiry often posed within interpretive social scientific research (e.g., Jackson, 2005; Kleinman, 1988; Turner, 1981)¹. To go further, 'Which visions of life, which aspects of their selves, which moral values, which social worlds do they see as most endangered by illness? Which unanswered questions seem most unbearable? Which meaningful ways of living seem possible?' These questions tap into what have been called the "biographical disruptions" (Bury, 1982) and "existential disruptions" (Little, Paul, Jordens, and Sayers, 2002) of illness experiences—ultimately, the destabilization of storied identities and meanings.

I asked a second question, 'How are discursive conditions affecting the stakes in question?,' in order to place biographical and existential challenges within important linguistic registers of cultural meanings. Some of the most prominent discourses drawn into my research include mythic allusions to cancer 'battles' and 'journeys,' images of young adult development and its 'arresting' in chronic illness, and moral prescriptions of where cancer comes from.

¹ "What is at stake?" is both research question and rhetorical device, affirming that people's stories communicate particular needs and values, however implicit, disputable, or insignificant they may appear to be. Much of the work of interpretive research is to understand the major stakes of a story in their personal and social contexts.

I hoped to perform two tasks in my dissertation project. First and foremost, I wanted to explore what is of most importance to young adults with cancer². Young adult cancer is relatively invisible within medical communities compared to pediatric or geriatric cancer, in part because out of an estimated 187,000 new Canadian cases of cancer each year, young adults make up just over 7000 (Canadian Cancer Society, 2013). I found that the scant research conducted with young adults was often summarily detailed, brief overviews of common themes or surveyed concerns. Though they are comparatively few, young adults living with cancer are likely more complicated than what I saw as ‘ideological’ depictions of them within the research. As with older cancer patients as well (e.g., Hammond, Teucher, Duggleby, and Thomas, 2012), their stories are thick with nuanced and multi-layered meanings produced out of messy everyday lives, and although it is harder to explicate these, both our understanding and our care of people with cancer suffers without them.

Second, in a critical move, I wanted to open up the space of possibilities for young adults. I recognized both the values and limits of certain discourses in illuminating illness experiences. While respecting that current dominant images about cancer and young adulthood can help patients and their families to make sense of their experiences, I wanted to problematize the origins and effects of such ideas. For instance, claims that unflinching positive thinking, strict diet, and daily exercise will both prevent and cure cancer are hard for me to take; I find in them not just practical advice but also more sinister moralized judgments about individual responsibility and self-surveillance. I worked to question the ‘naturalness’ or ‘inevitability’ of certain ways of talking about cancer by recognizing the diversity of individual stories and meanings of illness.

² Definitions vary of young adulthood, but for this project a frame was chosen between 18 and 45 years of age. I explain the difficulties and reasons around defining young adulthood in the following chapter.

Dissertation Overview

The remainder of this introductory chapter develops my reasoning behind choosing the above two tasks among many candidates. Some personal biases require insertion into my reasoning, as illness and death are not foreign subjects to my life history. I also carry with me professional horizons of understanding, conceptual tools that may spark flashes of illumination onto the foggy territories of illness. Accounting for these interpretive lenses demands a foray into ideas and circumstances beyond young adult cancer specifically, into broader debates about what is meant by experience, narrative, and discourse in the context of illness.

My fundamental argument throughout this dissertation is that how language is used has significant impact on people's experiences of suffering and healing. This perspective builds upon philosopher Paul Ricoeur's (1986) understanding of language as an event or act: "something happens when someone speaks" (p. 77), he or she projects a "proposed world" that implicates the life of the person speaking as well as those who are listening (Ricoeur, 86-87). What is at stake for people in times of crisis is revealed within this narrated world along with its many manifest and latent (or metaphorical) references (Ricoeur, 1984, p. xi). Furthermore, both people's stories and the metaphors within them "belong to the same basic phenomenon of semantic innovation"; they produce "meaning-effects," they construct representations of selves and worlds in attempts to "redescribe a reality inaccessible to direct description" (p. ix-xi), in this case, lived experiences of cancer that may be difficult to comprehend or communicate. In these innovative uses of language, people may project a wide range of meanings and identities around illness—what I will call 'moments of meaning' and 'moments of being'—to which the audiences of health researchers and care providers must be receptive if they wish to understand what is most important to people with cancer.

I have postponed until chapter 2 a more focused literature review and discussion of representations of young adult life and how chronic illness is perceived to affect it. I evaluate and criticize select discourses that operate within oncological contexts, especially biomedical discourses about the ‘distinctness’ of young adult cancer and psychosocial discourses about its disruption of ‘developmental tasks.’ Most relevant to my project is the normative trajectory of narrative order and self-authorship within discourses that intersect psychosocial oncology and theories of narrative identity development. In sum, I challenge these “normalizing ideologies” (Becker, 1997) of young adulthood for their common omission of potentially valuable and relevant information on personal histories, social worlds, and cultural shapings of experience. In order to complement these discourses, I propose a more critical psychosocial oncology aimed at recognizing the multiplicity of cancer stories and the complex biographical and existential effects of chronic illness signified by them.

Chapter 3 begins by addressing the lingering interpretive issue among illness researchers of the ‘crisis of representation,’ followed by what I see as my own interpretive task in this study. Herein I indicate my preferred theoretical perspective, critical phenomenology, as a dialogic approach between structures of lived experience and structures of power. Following my theoretical perspective are my philosophical assumptions about knowledge (i.e., social constructionism) and reality (i.e., weak realism). Given my interest in narrative constructions of selves and meanings, I take on a narrative analysis methodology from Catherine Riessman (2008). In the chapter’s remaining pages, I provide an overview of the participants of this study, including some germane characteristics about their work, home, and oncological lives.

The remainder of the dissertation consists of three analytic chapters, each addressing biographical and existential issues within young adults’ narratives of cancer and critically

evaluating the possibilities and limits of narrative order and self-authorship within this context. Across the chapters I engage with what literary theorist and physician Rita Charon (2008) called “narrative medicine,” studying the relevance of stories to understanding illness experiences and directing care. What she identified as clinically relevant features of illness narratives (i.e., time, frame and form, character, ethics, and the teller-listener relationship; p. 40) I adapted and expanded into my thematic division of the chapters (i.e., narrative genres, identities, and moralities). Some features, like plot and time, are integrated into the whole report, for a staple practice of narrative analysis is to keep the causal and temporal movement of stories “intact” (Riessman, p. 53). I introduce more review of the literature as it pertains to the subject of the chapter (including paradigmatic analyses of illness narratives like Hunsaker-Hawkins, 1993) and bring different perspectives into dialogue with the narrative analyses.

Although this is not a sequential thesis, the analytic chapters share an overarching thread in the sense that they each approach the issues of narrative order and self-authorship from three different angles. To begin with, chapter 4 includes discussion of the dominant *genres* young adults used to frame their stories and make meaning of their experiences. The question here is whether narrative forms serve the imperative of narrative coherence. I lean upon some contemporary literary work on illness narratives to explore a variety of genres adapted and manipulated in young adults’ accounts: battle stories, recovery narratives, journeys, mysteries, and chaotic narratives. Interested in going beyond categorization of narratives, I explore how people innovatively employ multiple genres in their stories, producing what we may think of as particular ‘*moments of meaning*.’ I conclude that while these creative moments sometimes lend more order to illness narratives, they may also produced more chaotic narratives that expose the limits of narrative order and reveal some the other stakes involved in young adults’ stories.

In chapter 5, I shift focus to the possibility of narrative *identities* to provide a sense of agency, which could be read as an avenue toward self-authorship. Narrative identities are analyzed in four interrelated ways. First is an extended look at the liminality of cancer experience, including the period of ‘separation’ brought on by symptoms and diagnosis, the ‘struggle’ period of treatment, and the tenuous as well as sometimes unattainable ‘consummation’ period of post-treatment. From there, I build upon the previous chapter by looking at the influence of mythic figures—often linked to prototypical plots—in shaping people’s narrative identities. As part of my critical evaluation of self-authorship, I analyze the extent to which young adults used these myths to construct themselves as agentic actors within the lifeworld of illness and who have moved on from the liminality of cancer. I find in this appropriation of myths numerous ‘*moments of being and non-being.*’ I then show how these identities are negotiated and contested in interactions with other actors involved.

As an extension of analyzing mythic identities, I look at the young adults’ developmental identities through and against dominant expectations about young adult identity, emphasizing career, family, and independence. No matter which myths were used, it seems that they served more than just the function of affirming agentic and re-integrated selves. Sometimes mythic identities helped young adults express the liminality and fragility of selfhood in illness. Based on participants’ resistance to reducing meaningful and generative living to achievement of these identities, I propose that we could recognize the legitimacy of these diverse and alternative ways of (non)being by redefining development in this context as “changing participation” in dominant discourses (Rogoff, 2003).

Chapter 6 is framed within the context of “remoralization” (Kleinman, 1988), often perceived as a necessary condition of making meaning of suffering and establishing personal

responsibility for healing. Herein I speak to the existential questions that participants asked themselves, their struggles to understand the origins of their illnesses, and their ideal images of the future. I found that the young adults worked toward and against remoralization, sometimes resisting moral explanations of cancer and often suggesting overdetermined moral origins. Considering their “subjunctive” explorations of morality (Good, 1994), it became clear that there were many different ways the young adults confronted the moralization of their cancers and the call to take personal responsibility for recovering from disease.

I draw my dissertation to a close in chapter 7 by, first, summarizing the knowledge of young adult cancer experiences developed out of this project. Basically, the ideological construction of young adulthood finds its limits in the lived realities of young adult cancer. From there, I provide two major implications from the research project: a) the complexities and the chronicity of psychosocial concerns demand us to reconsider our expectations of young adults with cancer, and b) what I call ‘critical witnessing’ offers a useful and complementary narrative approach to medicine directed toward “therapeutic emplotment” (Mattingly, 1998) and “agentivity” (Bruner, 1990). I end my dissertation considering some important limitations of the study and future directions for further research in this area.

My dissertation is like a dance with the young adults’ stories—admittedly clumsy sometimes—meant to show within them both moments of structural rhythms and creative improvisations. Through various twists and shifts of direction, I try to show their stories were not entirely their own, yet they could not be simply reduced to external categories, themes, or types. This delicate pendulum of negotiated meanings, I hope, reveals young adults in the complexities of their lives and stories.

What's at Stake for Me?

I would be deceptive if I claimed to have no stakes, graduation excepting, in the knowledge produced in this research project. Though in some schools of thought the following may be seen as an admission of clouding biases and unprofessional prejudices, I see my own stakes in this project as primed fuel for rigorous study and as a requisite care for the suffering of others. We all have our “prejudices,” according to philosopher Hans-Georg Gadamer (1960/1989), and though they may be limited they enable sight, they are our eyes, they open the world to us from a particular angle (p. 267-270). Surely my own personal background has shaped my perspective on the world and, therefore, to speak of it is to disclose some of the conditions of my understanding.

What draws me to my current study of young adult cancer is what, at earlier points in my life, initially repelled me away from it: my own witnessing of family members dying of chronic illness. Particularly pertinent were the painfully evasive silences within my family, silences that precluded conversation with and about those who were ill. One might say these were times of non-witnessing, for according to medical sociologist Arthur Frank (1995) the “reciprocity of witnessing requires not one communicative body but a *relationship* of communicative bodies” (p. 143).

My desire to talk about illness and suffering now comes out of a squelched craving to be present for family members who were severely ill. While a teenager, I had witnessed an unwillingness to engage the subjects of illness and death when my dearest relative, my uncle Jack, died of terminal leukemia. More recently, I was absent at a great uncle's funeral partly because I was not told of his death until the day before the procession and partly out of anger for such slow and weak communication in an age of cell phones and email messaging. I was not

even aware until later he had been living with terminal cancer for the last six months. For a time I was enraged and in furious despair. Regardless of whether telling me my great uncle was dying would have distressed me, or would have been an awkward subject to raise, or would have run counter to Uncle Bob's own wishes to conceal his illness, I was deeply incensed by what I saw as utter failures to communicate.

I wanted to be there with and for him, as I was while my grandmother, Josie, was dying of coronary heart disease only four months earlier. She and I *were* able to talk, I was able to say goodbye, and her death consequently weighed like a feather on my heart in comparison to my great uncle's death. I felt that I could do no better service to those I loved than to bear witness to their suffering, to talk with them about their fears, to try to understand what they were experiencing (if only from the distance afforded by good health). I felt deprived of the opportunity to establish that connection with my great uncle, and given the absence of speech around me I was immensely doubtful that he had such companionship from anyone else during his last days.

I eventually accepted that I could not talk about illness and death with my family. I quietly pursued these matters on my own, taking an interest in my undergraduate years in issues related to loss, grief, and death. I studied existentialist critiques of cultural practices of denying, avoiding, even forgetting about death and suffering. With the supportive encouragement of my undergraduate supervisor, Dr. Ulrich Teucher, I brought my professional interests to bear on personal passions in an Honour's project on existential concerns of dying cancer patients.

Looking back on it, I may have held an unfairly critical image of my family, or of the larger social practices of palliative care. I see my former self as taking a radically iconoclastic approach to common attitudes toward illness and death. I saw many illness discourses and

healthcare practices as processes of encryption whereby the truth of human suffering and mortality is shrouded; a truth that philosopher Simone de Beauvoir (1973) saw was “crushing” her dying mother and “when she needed to escape from it by talking, we were condemning her to silence; we forced her to say nothing about her anxieties and to suppress her doubts” (p. 59). These sentiments about the inability of families or health professionals to talk with patients about the human condition surely emerged from my own sense that the muteness within my family did more harm to my heart and mind than the deaths it kept hidden.

Over the last five years, from the beginning of my Honour’s Project until now, I have been humbled to rethink my crass iconoclasm. I have come to question what right I have to pontificate about others’ dealings with distress. I have come to appreciate that any efforts to talk about human suffering are fraught with difficulty, including my own. It is rarely an easy or a blunt conversation to speak of the most difficult events in our lives, and it was rather naïve of me to believe only a candid discussion would provide some understanding. Whether patient or family member, it is not always a failure to keep quiet.

I have come to see that, as the philosopher Jean-Paul Sartre (1988) has said, “silence is a moment of language; being silent is not being dumb; it is to refuse to speak, and therefore to keep on speaking” (p. 38). In other words, even in moments of total quiet can suffering be communicated and shared. My family’s silence around dying relatives spoke, not just to a crippling dread of death, but also (or alternatively) a practice of care through stoical anguish and soundless presence. Perhaps it was also an angry show of resistance, denial not of death’s existence but its authority. Perhaps the resistance was directed toward language and the dangers of putting incommunicable suffering into narrative order. I did not consider the possible ethics as well as the love expressed through their silence.

I have not entirely shed my iconoclastic leanings; I still feel that important aspects of illness are sometimes kept behind a veil by dominant discourses, and I do worry that the culture of illness in North America has serious flaws³. During sharply felt moments of injustice to patients, I sometimes make bold assertions as though they are indubitable truths. But, for the most part, I write primarily for the more temperate purpose of engaging the questions, “What is being ill like, what shapes the experience, and what can be done to understand those involved?” What’s at stake for me in my research is ensuring that illness experiences continue to be talked about and to be witnessed, which at least within my family do not always amount to the same thing.

Conceptual Tools

Negotiations of Meaning and Being

I engage with an interrelated set of concepts without which my research project would make little sense and would not likely be carried out. The following pages serve as introductions to the major concepts that I use in my analyses, to be elaborated on and added to in later chapters when it is pertinent. My disciplinary roots and interests are anchored in the psychology of illness; however, due to the complex nature of illness I have had to venture out of my home discipline to acquire other useful tools and perspectives. The resulting eclectic mix of concepts is theoretically grounded especially in interpretive but also phenomenological and existentialist traditions of psychology, sociology, anthropology, philosophy, and literature.

Above all, these traditions share a common space in highlighting: a) the *lived experiences* of illness; b) *narrative* constructions of meaning and being; and c) the participation of narratives within larger cultural and political *discourses* of illness. Out of negotiations between lived

³ For example, institutions that isolate patients from society, medical discourses that dwell only on bodies and not minds or relations, and moral judgments that individuals are responsible for the emergence of and recovery from their cancers.

experiences, narrative constructions, and cultural discourses emerge what I continually refer to as ‘*moments of meaning*’ and ‘*moments of being*,’ placements of the biographical and existential challenges of illness within specific representations of life. I flesh out these conceptual tools in turn and illustrate how analyzing negotiations of meaning and being in language may assist in understanding young adults’ most important concerns.

A) Lived Experiences of Cancer, Being-in-the-world, and Liminality

One of the primary premises of my work, inspired by Rosenthal, is that our understanding of what is at stake for young adults is weak without delving into the complex and concrete issues of their intimate lives. Knowledge of young adult cancer may be informed by a “thick description” of the personal and social lives of participants, enabled by “experience-near” research (Geertz, 1973). Yet, it can be problematic to talk about ‘experience,’ as it is and has been a subject of much debate. What does it mean, for example, to study ‘experiences of illness’ as a unit of analysis? How do we, as researchers, get ‘near’ experiences of cancer when we are relying upon retrospective narratives?

Illness experiences, as I understand them, are on-going transitions, subject to the flux and flow of days, months, and years since the onset of symptoms. However minute for some and ground-shaking for others, cancer can be a transformative or disruptive experience that may require reinterpretation of bodies, selves, relations, and worlds (Bury, 1984; Little, Jordens, Paul, Montgomery, and Philipson, 1998). The concepts of lived experience, being-in-the-world, and liminality discussed below serve as interpretive tools for understanding how lives may be transformed by illness. But, before we get there we need to consider various ways in which ‘experiences,’ as a theoretical concept, may be understood.

1. 'Experience' in Philosophical Discourses

Let's take a moment to think about experience on a philosophical level. It cannot be overstated that 'experience' as a concept is quite contested and multifarious within academic discourses. For example, the *Dictionary of philosophy and religion: Eastern and Western thought*, written by philosopher William Reese (1980), presented seven different dominant theories of experience (pp. 164-165), ranging from John Locke's empiricism to John Dewey's pragmatism. The *Dictionary of Philosophy and Psychology* (1901), edited by philosopher and early psychologist James Mark Baldwin, submitted a discontentedly critical perspective on the matter. Receiving contributions from John Dewey as well as William James, both known to write extensively about 'experience,' the book presents the concept as a knotted term within philosophy. Baldwin and co-contributor philosopher George Stout wrote, "The word is used so vaguely and ambiguously by writers on philosophy that definition is difficult" (p. 360). Their frustrations seemed to stem from the mosaic of meanings of experience within philosophy.

However, this critique of philosophy is unjustified. Ambiguity is a sign not of the failures of philosophy, but of the rich diversity of ways in which the term 'experience' may be interpreted and analyzed. From my perspective, what is more disconcerting is when this diversity is disengaged. For example, the fact that neither James nor Dewey provided any defence, or even supplied their own theories of experience—which are written in other texts of theirs—suggests an unwillingness to engage the subject, which seems anathema to the very process of philosophy (or, at least, to a Socratic dialogue toward knowledge). More recently, the *Cambridge dictionary of philosophy*⁴ (Audi, 1999) and the *Oxford dictionary of philosophy* (Blackburn, 2005) did not even include a section on 'experience,' an absence that may not have been an unintended

⁴ The Cambridge dictionary does have limited descriptions of two specific concepts of experience from within phenomenological and hermeneutic traditions, *Erlebnis* and *Erfahrung*, which will be brought up in a few pages.

oversight. Surely such theoretical evasion cannot help us to understand the concept or, for my purposes, to apply it within research endeavours. Researchers depend upon philosophical discourses in order to critically reflect upon such a complex and elusive concept; the way toward this reflection is not to shy away from the multiplicity of perspectives but to share and invite dialogue between them, in the way many philosophers—Reese (1980) among them—have done. It is in this spirit of multiplicity that I discuss different understandings of experience below within the health and social sciences.

2. ‘Experience’ in Medical Discourses

Let us look at experience as it relates more specifically to discourses of chronic illness. Medical oncology typically conceptualizes cancer experiences in terms of bodily happenings (e.g., Buckman, 2006). Above all is the process of cancer itself, which is described as a “disorderly and uncontrollable” division of cells, often ‘experienced’ through symptoms including lumps on the body, blood in excretions, or acute pain in localized areas (Buckman, 2006, p. 26-30). Other major ‘experiences’ are discomforting side effects from treatments like radiation rashes and chemo-induced nausea, and medical signs of remission or relapse such as white blood cell count (Alschuler and Gazella, 2010; Buckman, 2006). These experiences can range from short-term occurrences like hair loss, fatigue, and burning sensations to permanent conditions like infertility, amputation, and death.

It may sound redundant to say the body figures importantly into an adequate definition of cancer experiences. The account above constructs experience biomedically, with attention to biological processes going on in the body that may or may not be felt by the person. Whatever else may be going on in the world of cancer, what is most important is within the patient’s skin, often at molecular levels.

However, is experience *only* bodily in nature? Or, perhaps more accurately put, is the body *only* biological? Medical oncologist Robert Buckman (2006) argued that the mind has no effect on the emergence or course of cancer, disputing what he saw as popular ‘myths’ about cancer being psychogenic. Laudable though his defence is, he seems to divide mind and body in an absolute way, where one is hardly related to the other. His argument, like many medical discourses on cancer, seems to assume a Cartesian concept of mind, as an “inner theatre in which mental events can be observed to come and go” (O’Murchadha, 2003, p. 93) and where some homunculus overseeing the workings of the show notes the ‘experiences’ of the body. In other words, the extent of their connection is that the body experiences cancer while the mind interprets the body.

This ‘medical Cartesianism’ has some grounding in the perceptions of people who fall ill. Sometimes people who suffer severe illness talk about a division between their bodies as sites of what is happening and their selves as an outside observer (e.g., Carel, 2008; Good, 1994; Middlebrook, 1998). However, this felt distance does not necessitate an ontological distinction; according to some traditions of understanding illness, to which I now turn, it does not make sense to hold the body as a neutral object of experience and the mind as a distant, interpreting subject of experience.

3. ‘Experience’ in Phenomenologies of Illness

Some more phenomenological traditions within injury and illness studies challenge the mind-body dualism as a fabricated distinction, one derived from rather than proved by alienating and disruptive experiences of pain and ailment (e.g., Leder, 1990; Scarry, 1985; Svenaeus, 2009). Body-self splits often experienced by people who are ill may be explained as instances of “dys-appearance” (Leder, 1990, p. 141-142), in which ruptures to the familiarity or integrity of a

person's body (as due to pain, irregularity, or exhaustion) partition it from the person's everyday experience of well-being (see also Csordas, 1994; Svenaeus, 2009). What phenomenological approaches to illness experience restore is a notion of *selfhood*. People are believed to be a bridged 'body-self' even if temporarily disjointed by bodily disturbances.

Within these perspectives, Cartesian dualism is replaced by a qualitative distinction between the material, objectified bodies (*Körper*) and phenomenological bodies (*Leib*) that are part of subjective, experiencing selves (Heidegger, 1987/2001; Merleau-Ponty, 1945/2002; Ots, 1994; Overboe, 1999). On the one hand, material bodies are objects, imposed upon by external forces from their environments (e.g., carcinogenic materials corrupting metabolic processes) and reacting via mechanical inner processes (e.g., uncontrolled malignant division of cells). On the other hand, phenomenological bodies possess subjective and "intentional" (or active) relatedness to the world around them; illness becomes part of a person's life, influencing how they see the world (e.g., as fair or unjust) as well as their actions in the world (e.g., making it to work in the morning).

Leib, a German word that is not by happenstance quite close to *Leben*, meaning "life," is often seen as intersecting with what we might call "lived experiences" (*Erlebnis*). The *Cambridge dictionary of philosophy* (Audi, 1999) indicates that *Erlebnis* is used to refer to experiences as lived, while *Erfahrung* is reserved for thematized or objectified experiences (p. 279-280). Lived experience "refers to an active self, to a human being who not only engages in but shapes an action" (Bruner, 1986, p. 5). There seems to be no account of action or self in medical definitions of 'experience,' or in medical perceptions of bodies as passive vessels of disease and treatment; when we study lived experiences, we study the manifold intentional ways in which a given event is responded to or "lived through" (Bruner, p. 3).

A parallel distinction can be made between *disease* as a biomedical object of enquiry and *illness* as a patient's subjective experiences (Kleinman, 1988). The former concept usually entails reified divisions between the patient and the diagnosis (or subject and object) while the latter affirms that people *live with* their condition. In a sense, cancer is 'personalized' through this different interpretive lens. Phenomenological studies of illness observe how lived experience is subjective and embodied, how bodies and worlds affect one another. Agitating aches can rupture relationships just as social isolation can instigate further feelings of pain. Furthermore, differences in illness experiences are accentuated to a much greater degree than in medical discourses⁵, as people have many different selves within a variety of local worlds.

Some may mistakenly see the collapse of subject and object as a defence of reductionism, in which the mind is reducible to physical material. However, phenomenologists are sternly against reductionism. Neither is mind seen as the amalgamation of neurons, nor is the lived *Leib* seen to be strictly bound to the material *Körper*. Mind and body go beyond physicality because they both relate outside themselves to the surrounding social and physical worlds, interactions that coalesce into what is often described as our "being-in-the-world" (Csordas, 1994, p. 10; Merleau-Ponty, 1945/2002, p. 183; Svenaeus, 2003). In this context, *being* may be understood as 'ways of existing' that people act out 'in the worlds' they inhabit⁶. 'Being-in-the-world' broadens the contours of mind and experience beyond a particular object (i.e., the squishy

⁵ It is important to recognize that medical practices do not necessarily emulate medical discourses. In her studies of physical therapy, anthropologist Cheryl Mattingly noted that although official medical doctrine tends to ignore the "phenomenological side of disease and disability," health professionals who work directly with patients sometimes (implicitly or unofficially) engage in this unrecognized model of care (p. 21). To go further, philosopher Anna-Teresa Tymieniecka (2001) respectfully wrote that medicine and phenomenology are not necessarily mutually exclusive, and if brought into dialogue can be "cooperative and complementary" (p. ix).

⁶ The term "being" has many permutations within the history of ideas and I do not intend to get lost within them. Of special note, however, is the German philosopher Martin Heidegger (1927/1962) because of his influence on how the term is used in phenomenological traditions. His notion of *Dasein* ("being-there") emphasized that our being is located 'there,' in particular historical and cultural worlds, and is something we constantly question and negotiate. I am deeply indebted to the tradition spurred on by Heidegger, as the argument that being may be always situated and interrogated are two key assumptions built into my uses and analyses of the term throughout my dissertation.

interior of the brain) while avoiding abstraction from the person's world (i.e., in an ethereal Cartesian soul).

4. Being Healthy and Being Ill

Health and illness are two notably different forms of being-in-the-world. The primary difference between the two, it may be argued, has to do with the nature of relating to one's local worlds of meaning. In particular, health is characterized by what medical philosopher Fredrik Svenaeus (2000) referred to as "homelike" being-in-the-world, when one is comfortable in one's body and in social settings, finds it easy to get around, and takes many assumptions about life for granted. "Unhomelike" being-in-the-world can indicate illness or another disruptive experience, when body and world seem strange, in tension, or uncooperative (Svenaeus, 2000). I adopt this framework for interpreting the structure of illness experiences.

"Unhomelike" estrangement in cancer can occur in many different ways. Philosophers of medicine Evandro Agazzi and Anna-Teresa Tymieniecka (2001) wrote of a "global" sense of disruption in illness: "we feel wounded 'as a whole,' it is our whole life that is affected, we have the impression of an adverse 'destiny' that is hitting us" (p. xii). Medical anthropologist Byron Good (1994) expanded this global sense of disorientation into several related unhomelike experiences. To begin with, he wrote of precarious relations formed between bodies and selves (as already mentioned) as well as distracted awareness and fatigue from irritable pain (Good, p. 124-127). Examples abound in the research literature of cancer patients experiencing unfavourable changes to ability, embodiment and/or identity (Blinderman and Cherny, 2005; Carter, MacLeod, Brander, and McPherson, 2004; Halldorsdottir and Hamrin, 1996; Little et al., 1998; Little et al., 2002; Sand and Strang, 2006; van Manen, 1998).

Good also observed altered time perceptions and fears about lost time, death, and dying (p. 126-127), which are quite prevalent among many studies of cancer patients (Blinderman and Cherny, 2005; Fife, 2005; Griffiths et al., 2002; Klem, Miller, and Fernsler, 2000; Landmark, Strandmark, and Wahl, 2001; Moadel et al., 1999; Morita, Tsunoda, Inoue, and Chihara, 2000). In particular, people may start to place doubt upon their assumptions about time (e.g., how much of it they still have, when certain life events are supposed to happen), most often feeling they were overly generous in their previous estimations.

Another set of unhomelike and alienating experiences have to do with meaningful activities and social interactions. In some situations of cancer, everyday routines and responsibilities can be subverted by unavoidable symptoms and unwanted time commitments (e.g., frequent follow-up tests, long resting periods) that preclude completion of other daily tasks (Good, p. 127). Many people worry about the effects of cancer and treatment on personally meaningful projects, and feel unable to perform actions that used to be effortless (Carter et al., 2004; Halldorsdottir and Hamrin, 1996). These changes to everyday reality may produce a rift between patients' lived worlds and the lived worlds of their loved ones. The resulting social gaps can be flooded with suffocating detachment and misunderstanding (Good, p. 125), repeatedly reported by people with cancer (Blinderman and Cherny, 2005; Halldorsdottir and Hamrin, 1996; Little et al., 1998; McKenzie and Crouch, 2004; Morita et al., 2000; Sand and Strang, 2006; Thompson, Jensen, and Bonde, 2007).

The extent and longevity of unhomelike being obviously varies. Writing about shifting perspectives during illness, sociologist Kathy Charmaz wrote that the sense of change depends on "the meanings that [people] attach to their illness, the way that they experience it, their 'life structure' (Levinson et al., 1978), their age, and whether or not they can merge the illness into

their daily routine” (p. 283). She reported that young adults are more likely than older adults to see illness as an interruption (p. 58-62), a “temporary crisis” in which recovery will occur “soon” (p. 13). That said, regardless of age or expectation, some cancers may become more “intrusive” into people’s lives (p. 42-48), even becoming “immersed” in their daily routines and perceptions of self (p. 76-97). Serious illness may perpetuate unhomelike being indefinitely, a daily obstacle that is never truly overcome.

We may trace the origins of unhomelike being to a number of different sources. In an essay on ‘falling ill,’ Svenaeus (2009) argued that above all it is one’s body that causes the disruption: “illness makes us feel our own bodies: it reveals the body to us in different ways, through making it heavy, stiff, hot, nauseated, plagued by pain, twists, jerks, shivers, etc.” (p. 59). He contrasted his position against that of Jean-Paul Sartre, who he read as saying illness is more of a social judgment, wherein the “gaze of the other” (especially a physician) imposes “outside” interpretations on one’s body (Svenaeus, p. 58). Arguably, unhomelike being may emerge from felt discomforts as well as suggestions from one’s social world. Contested illnesses like chronic fatigue syndrome serve as an excellent example, for frequently in such cases there are multiple, contradictory sources; patients often insist upon recognition of what they feel as physical ailments while more skeptical physicians apply mental or psychosomatic diagnoses upon them (see e.g., Banks and Prior, 2001; Cohn, 1999; Dumit, 2006)⁷. The source and meaning of their unhomelike experiences are thus in dispute.

Sartre (1960/1968) recognized multiple origins of illness in an insightful footnote to his *Search for a Method*: “in one respect, illness is social” as “society...*decides* its sick and its dead. But in another respect, it is a certain manifestation—a particularly urgent one—of the material

⁷ This example is also relevant to young adult cancers. As will become evident throughout the analyses, unfamiliarity with young adult cancers among participants’ general practitioners led to a period of contestation over whether their symptoms represented physical illness.

life, of needs, and of death” (p. 103-104; original text). Alienation in illness, he observes, may come from an entanglement of embodied and social sources and, it is implied, may produce an array of different effects; some illnesses are socially recognized while others are made invisible, and the ‘disability’ of the latter are in part due to internalized feelings of invisibility and lack of access to public spaces (e.g., Chouinard, 1994; Clark and James, 2003). We may thus say that illness is unhomelike being-in-the-world to varying degrees instigated and defined by bodily happenings, self-perceptions, and social relations.

5. Illness Experiences as Existential Disruptions

Unhomelike experiences can cause existential disruptions, in which the “assumptive worlds” (Attig, 2001) that frame our everyday experience are ripped from their seams and shredded; in a word, our selves and meanings are “unmade” (Scarry, 1985). It is the movement between unmade and remade lifeworlds that interests me. Existential disruptions are quite common among cancer patients and can lead to various forms of physical, psychological, and social distress (e.g., Henoeh and Danielson, 2009; McKenzie and Crouch, 2004; Williams, 2004). For some people the uncertainties around how to understand themselves and their worlds can be more potent, more fundamental, than the physiological trials of cancer symptoms and treatment. For example, young adult Kairol Rosenthal reported “existential funks,” along with “nail biting and temper tantrums,” as the “bedrock moments” of her time with cancer (p. 146).

Psychosocial oncology research has been bringing the existential challenges of cancer and their clinical effects to the attention of care providers since at least the 1980s (Rowland, 1990). In contemporary discourses they are often defined as reflections, queries, fears, or doubts about significant, universal aspects of human existence. Some concerns that are typically categorized as existential among cancer patients include death awareness and anxiety,

perceptions of time, and experiencing a sense of (lost) freedom, hope, and/or meaning (Bolmsjö, 2000, 2002; Jacobsen, Jørgensen, and Jørgensen, 2000; Moadel et al., 1999; Morita et al., 2000). Others within the field have, perhaps more accurately, identified existential disruptions as the destabilization of a sense of being and meaning, and subsequent efforts to reconstruct them (Blinderman and Cherny, 2005; Breitbart and Heller, 2003; Carter et al., 2004; Coward, 1997; Fife, 2005; Griffiths et al., 2002; Halldorsdottir and Hamrin, 1996; Klem et al., 2000; Lee, 2008; Tang et al., 2007; Vickberg et al., 2001).

Research on existential concerns has been conducted in a variety of different settings in Canada (e.g., Lee, 2008; Mount, Boston, and Cohen, 2007), Japan (e.g., Morita et al., 2000), Great Britain (e.g., Griffiths et al., 2002), Sweden (e.g., Ramfelt, Severinsson, and Lützen, 2002; Sand and Strang, 2006), Israel (e.g., Blinderman and Cherny, 2005), and many others. Despite the diversity of socio-geographical locations, many health researchers tend to presume a homogenous nature to cancer patients' existential concerns, such as their fears of death. These assumptions may be grounded in some existentialist traditions of anthropology and psychology, wherein existential concerns get constructed as lonely, individual struggles between finding one's own significance in the world and facing one's inevitable biological destiny (e.g., Becker, 1973; Frankl, 1946/1984; Yalom, 1980, 2008). Although these are helpful ways of thinking about cross-cultural concerns when confronting mortality, issues of being and meaning get taken out of the worlds within which they take form (similar to that of medical Cartesianism).

More critical and context-attentive studies of illness place existential challenges within cultural constructions of self and social systems of meaning (e.g., Becker, 1997; Kleinman, 1988; Good, 1994). Sociologist Beverly Rosa Williams (2004) emphasized that, "because humans are social creatures who construct meaning from encounters with others...existential distress, like all

experiences of suffering, is rooted in incoherence and disruption of relations with self and others” (p. 27). In a medical setting, these local relations include a host of people who may or may not provide support, understanding, care, and resources (e.g., family members, friends, physicians, nurses, social workers, insurance agents, etc.), as well as the larger milieu within which a person’s community interprets, talks about, practices, and makes policies for healthcare. The critical side to these studies entails: a) exposing culturally received or sedimented meanings that serve to limit the available ways of being by ‘naturalizing’ only a few, and b) listening for instances of resistance to those sedimented meanings in people’s narratives.

Existential concerns may address broader (perhaps even universal) issues, what existential anthropologist Michael Jackson (2008) referred to as “recurring symbolic motifs” such as “the need to be recognised, healthy, loved, happy, or free, to have security, wealth, an identity, a fulfilling job, a family or friends, and to do well in life” (p. x). However, they also emerge from within particular social and cultural contexts and, therefore, may require research and support that is attentive to those contexts (Jackson, 2008; Kleinman, 1988; Williams, 2004).

Existential questioning can be quite easily but perhaps mistakenly seen as inherently distressful and harmful. An abundance of literature from meaning-centred psychiatry and philosophy affirms that questioning our being can enhance our sense of meaning (e.g., Breitbart, Gibson, Poppito, and Berg, 2004; Frankl, 1946/1984; Heidegger, 1927/1962). Arrays of published narratives of cancer speak of personal development and discovery born out of initial disruptions, fears, and difficulties; such narratives employ hopeful languages, for example, of metaphorical “triumph” (Lerner, 1991), spiritual “reflection” (Matthews, 2007), and personal “growth” (Stefaniuk, 2009).

These positive transformations seem to result from alienation, which can breed a critical distance from limited or oppressive discourses, assumptions, and ways of living. Writer Virginia Woolf (1926/2002) wrote that lying in bed, no longer part of the “army of the upright,” people in the midst of illness are afforded reflection of their taken-for-granted worlds; they are able to “look round” at their lives from a new angle and “look up...at the sky” to ponder existence (p. 12). Literary critic Anatole Broyard (1992) wrote of his advanced cancer as “like a great permission, an authorization or absolving...All your life you think you have to hold back your craziness, but when you’re sick you can let it out in all its garish colours” (p. 23). A bit more romantic than necessary perhaps, but Woolf and Broyard are pointing to a paradoxical sense of liberation that can come out of disruption, where halting unfamiliarity with the world can, in turn, redirect the paths of people’s lives in sometimes enriching directions.

We have to be cautious about imposing an imperative of positive transformation upon cancer patients, as such discourses can sometimes have that effect (e.g., Delvecchio-Good, Good, Schaffer, and Lind, 1990; Lazarus, 1998; Salliant, 1990). In many cases, unhomelike being can be antithetical to ‘well being’; however, there are times when, through reevaluation and resistance, illness may lead to desired personal and perhaps even social changes. Social worker Kimberley Thompson (2007) saw these opportunities emerging from the “creation of a liminal space...in which one has the potential to experience themselves and their social surround outside of preconceived categorical notions” (p. 340-341). In these moments, existential challenges may be reframed as releases from dissatisfying lives and opportunities for remaking peoples’ worlds in healing and liberating ways.

6. Liminal Being during Illness

Studying lives affected by cancer demand attention to the liminality of illness experience. Though illness may be referred to as a ‘state’ of being, this language can be problematic. Cancer is often ‘lived through’ as a process, a transition between moments of meaning and between moments of being. Over time being chronically ill can entail a variety of changing, unpredictable states. Symptoms may for an extended period remain moderate but have sharp, sudden spikes in intensity. Cancers may be diagnosed at a specific stage (0 to 4), but their stage may vacillate depending on the efficacy of treatment, evidence of remission, or emergence of metastases. Cancer treatment itself comes in waves: radiation and chemotherapy treatments operate in shifts, with days or weeks off before the next round.

Thus, it seems dubious to refer to cancer as ‘an’ experience, in the singular; it seems to be many experiences—sometimes continuous, other times erratic or fluctuating—happening over time. Anthropologist Victor Turner (1986) was quite reflective about what it means to ‘experience’ something; he looked to the etymology of ‘experience’ and found transitional meanings in its roots: the Indo-European *per* meaning “to attempt, venture, risk”; German cognates of *per* meaning “fare, fear, ferry”; and the Greek *perao* meaning “I pass through” (p. 35). In sum, Turner concluded that the concept of “experience is linked with peril, pirate, and experiment” (p. 35), embodied in many cancer patients’ experiences as feeling closer to death, robbed of time, and desperate to try whatever works.

Cancer experiences may thus be seen as inherently transformative, though of course to widely varying extents. Living through cancer in young adulthood may manipulate bodily shape or functionality through surgical therapies, change the course and goals of people’s lives, lead to more intimate or more strained relationships with family, and catalyze advocacy work in hopes

of creating more awareness of young adult cancers. In all of these examples there is a period of “liminality” in which some calm, undisturbed aspect of life is agitated, sometimes shaken to its foundations. We can see here that unhomelike being is a form of liminal being, where much of one’s former life is made strange. Liminality is any process of flux within the structures of everyday social life, leading to passages from one status, identity, or stage to another (Turner, 1966; Van Gennep, 1909/1960). In the process, people’s selves and meanings are radically transformed.

Chronic illness can produce *liminal* selves and meanings wherein one’s perceived positionings in local social worlds are disrupted, reinterpreted, and renegotiated. This is not a new concept; for instance, anthropologist Robert Murphy (1987) wrote of his liminal experience of disability brought on by a tumour in his spine: “The sharp edges of my self had become porous and weak” (p. 42) and “I had changed in my own mind, in my self-image, and in the basic conditions of my existence” (p. 85). He felt a “revolution of consciousness” and a “metamorphosis” that set him and others with chronic conditions apart from the larger society (p. 87). Connected in their otherness, he saw people with disabilities as an “undefined, ambiguous people” (p. 131) who suffer a “deprivation of our social being” (p. 227). Murphy did not see this as having an inherently negative connotation; he suggested these liminal lives were “positive and creative, for their self-assertion is a profound celebration of life” (p. 161). Liminality has been since used as an interpretive frame for understanding cancer experiences (e.g. Little et al., 1998; Thompson, 2007) and similar themes—of transformation, isolation, and creation—may apply to the young adult narratives I studied.

Turner (1969, 1986) broke down liminality into three phases of transition, which seem to resemble some of the transitions articulated by cancer patients. The first phase is “*separation*” or

detachment from the usual order of things, producing a shock response in its unexpected, drastic, or unpredictable emergence (Turner, 1969, p. 94; Turner, 1986, p. 35-6). Many people report feeling numb or disoriented after hearing their diagnosis of *cancer*, a disease thick with cultural associations to death and loss. Being told one ‘has’ cancer can be a surprising or even humiliating exposure of vulnerability to many people.

As people are making decisions about their care, going through and recovering from sometimes debilitating treatment, and attending follow-up visits to see if they are in remission, they may be all the while trying to grab hold of some understanding of their passage. This involves Turner’s second phase of “*struggle*” to find meaning, wherein one tries to make sense of what’s going on, where it might have come from, and how best to proceed (Turner, 1969, p. 94-103; Turner, 1986, p. 36).

Finally, the aggregation or “*consummation*” phase entails an arrival, a restoration of stasis or continuity in people’s circumstances (Turner, 1969, p. 94-103; Turner, 1986, p. 36). At this stage, according to Turner, some sense has been made of the ordeal, some representation or story of lived experiences has been produced. Importantly, because cancer is not always ‘cured’ or guaranteed to never return, there is often no clear finale to the experiences. The uncertainty of the future, coupled with enduring changes for better or for worse, can keep people in a continual state of liminality (Little et al., 1998; Thompson, 2007). Nevertheless, many cancer patients who recently finished treatment talk longingly about arriving at the three-year or five-year mark of their remission status, which they believe will signal the ‘end’ of the experience and a return to ‘normal’ (see e.g., Jain, 2007).

7. Conclusion: The Complexity of Lived Experiences

To conclude this first section on my conceptual tools, there may be much more going on in illness experience than biological happenings, perhaps more than can be comprehended. Though important work, accounting for the diverse interactions between bodies, selves, and worlds during periods of illness can be incredibly difficult, if not impossible. Jackson (2008) summarily wrote, “We can never grasp intellectually all the variables at play in any action or all the repercussions that follow from it, partly because they are so variously and intricately nuanced, and partly because they are embedded in singular biographies as well as social histories. However, it is possible...to produce edifying descriptions of what Virginia Woolf (1985) called ‘moments of being’ when we are afforded glimpses into what is at stake for the actors, and how they experience the social field in which they find themselves” (p. xxv).

These “*moments of being*”—and we may correlatively add ‘*moments of meaning*’ that show what life with cancer is like—come out of expressions people construct of their experiences. While one is living through cancer, one is in the separation and struggle phases marked by what could be called “*mere experience*” (Turner, p. 36) or “*experiencing*” (Gendlin, 1997, p. 1-4)⁸, which are not yet meaningfully expressed. Narratives perform or bring into expression what their authors find most relevant and most at stake at the time. It is thus to the arena of narratives that many illness researchers turn in order to understand illness.

B) Moments of Meaning and Being Produced in Illness Narratives

For all their attempts to witness suffering, families and friends of cancer patients cannot fully comprehend the physical pains, existential anxieties, and social challenges that they face—often enough patients themselves cannot sort these issues out. For my part as a social researcher,

⁸ Gendlin used the gerund form of experience to denote it as a constant process, as distinct from the noun form that is a relatively static or at least bounded account of action.

I cannot claim to have access to others' day-to-day flow of *experiencing*, as though “through some magical intrusion into their consciousness” (Geertz, 1986, p. 373). What we do have some access to are the meanings of illness people articulate when they speak, write, or in any way express their experiences. But, how do people *make sense* of cancer experiences? And where do meanings of illness come from? For my interests, I look to illness narratives as situational productions of moments of meaning and moments of being.

1. ‘Meaning’ in Intellectual and Health Discourses

Discourses of meaning abound in academic literature, making the concept as fraught with complexity and confusion as the concept of experience (e.g., Eagleton, 2007; Ogden and Richards, 1927). *The Cambridge dictionary of philosophy* (Audi, 1999), for example, wrote of meaning in a multitude of senses: the *literal* or definitional meaning of a word, a person’s *intended* or purposive meanings, *cognitive* meanings or mental images associated with certain words or signs, the *referential* meanings or objects pointed to in the world, the *expressive* or performative meanings in the elocutionary act, and so on (p. 545-550). The dictionary observed that the wide range of theories out there locate the basis of ‘meaning’ within either thought, the context of each speech act, and/or social practice (p. 546).

One dominant way of thinking in Western intellectual traditions is that of a “correspondence theory of meaning” (Gamut, 1982/1991), in which language is believed to possess strictly *referential* meanings; our words, it is argued, refer straightforwardly to the world of experience. Within these traditions, meaning is perceived as “a relation between the symbols of a language and certain entities which are independent of that language” (Gamut, p. 2). Thus conceived, meanings of illness would be the ‘real’ events pointed to in people’s stories. This referential perspective is often challenged within some philosophical traditions as a “myth of

objectivism” (Lakoff and Johnson, 1980; see also Derrida, 1967/1976; Ricoeur, 1976), wherein it is taken for granted that the meaning of words is independent of their use or purpose within particular contexts. As I have shown above, illness is a way of being-in-the-world and makes sense only in relation to its placement within the surrounding world of culture and action.

The health sciences seem to be dominated by a different, more idealist conception of meaning located primarily in *cognitive* processes. People making sense of illness or other stressful events are often seen to go through strictly mental “appraisals of meaning,” or reevaluations of beliefs about self and world (e.g., Park and Folkman, 1997; Richer and Ezer, 2000). This appears to be an extension of the medical Cartesianism around illness; while experience is allegedly tied to an objective body, meaning is perceivably held within a more subjective mind. The same limitations of decontextual understanding thereby apply: the body is displaced from its lived roots in subjective and intersubjective worlds, and the mind is abstracted from its location within embodied and social life.

2. ‘Meaning’ as Expressions

Some social scientific and literary discourses of illness ground meaning in performances and cultural idioms (e.g., Kleinman, 1988; Good, 1994; Hunsaker-Hawkins, 1993). Within these discourses, expressions are seen to produce or make apparent culturally available ways of meaning and being. For instance, many stories of illness repeat familiar, cultural plots—like “quests” into the foreign lands of hospitals—in creative and informative ways (Frank, 1995). Stories do not necessarily reflect real events in the individual’s world or pre-narrative assessments of meaning, but they articulate certain customs and strategies for telling stories that others may understand.

I find the attention given to *expressive* meanings to be potentially more rewarding than *referential* or *cognitive* meanings in placing people's stories of illness into personal and social contexts. Expressive meanings are not necessarily pre-linguistic, static things residing in our minds, but more likely '*productions*' inspired by individual creativity and broader social mores around expressing illness experience (Good, 1994, p. 142-144). But, I do have to contend with a paradox in seeing expressions as productions: they do not necessarily correspond to what happened during periods of illness or what people are thinking, yet they are the only way we can learn about the experiences and thoughts of others (Kleinman, 1988; Geertz, 1986).

What, then, do expressive meanings have to do with lived experiences? Expressions are "naturally occurring units of meaning" (Turner, 1986, p. 35) in which the flow of on-going *experiencing* gets reformulated as *an* experience with demarcated form (Gendlin, 1997, p. 4)⁹. Although there may be pre-communicated, mental meanings (Park and Folkman, 1997) or bodily "felt meanings" (Gendlin, p. 233-234) that put illness to order, the meanings we as social researchers have access to are outward-projecting expressions of suffering and healing. Because our only bridge-ways into others' lives are their gestures and signs, educational researcher Melissa Freeman stated, "inquiry into being should focus [on] the conceiving and performing of being" (p. 929). Our work operates within language and it is therefore useful to think of meaning and being within linguistic frames.

Selective focus on expressive meanings does not mean outright dismissal of the mental meanings of a thinking mind or the felt meanings of a lived body. Post-structuralist Roland Barthes (1966/2000) was quite radical in writing that, "'What takes place' in narrative [or other expressions] is from the referential (reality) point of view literally nothing, 'what happens' is

⁹ The distinction is comparable to that of *Erlebnis* (i.e., experience lived through) and *Erfahrung* (i.e., experience conceptualized) discussed above.

language alone, the adventure of language, the unceasing celebration of its coming” (p. 113). It may be difficult to make an unburdened leap from expressive meanings to ‘underlying’ or ‘real’ indications of experience, but it seems too drastic to conclude that expressions point to “nothing” beyond language. Such an attitude toward expressions comes dangerously close to overlooking the pain and suffering that is often not only the content of but also the catalyst for stories about illness.

There is more to expression than blowing hot air or playing with words; that we are moulded by culture and language does not make our utterances hollow. Rather, with the help of larger systems of meaning, illness experiences can be communicated, shared, and somewhat understood. Patients use cultural meanings to form a “living testimony,” an account of injuries and injustices inflicted on their body-self (Frank, 1995, p. 140) and of the “distinctive moral and spiritual form of distress” they have lived with (Kleinman, 1988, p. 26).

Health researchers need to consider the powerful impact of language on the process of understanding our own lives and deaths during illness. In Susan Sontag’s (1978) analysis of illness metaphors, she found that the common language used to talk about illnesses such as tuberculosis and cancer have a huge impact on how people perceive the causes and cures of illness. For instance, in the 19th century tuberculosis was typically spoken of as a disease of excessive passions, poor hygiene and inadequate food, and an affliction of the eccentric character; in the 20th century (and to some extent today), cancer was discursively linked to repressed passions, wealth, and shameful bodily processes¹⁰ (p. 10-21). In these contexts, dominant metaphors may not represent the ‘true origins’ of illness, but they affect how people make sense of and act on their suffering.

¹⁰ This cultural association taps into some of the common forms of cancer originating in organs of reproduction, sexual activity, and excretion, such as the breast, colon, bladder, cervix, testicles, etc.

Instead of resorting to rash skepticism, we can attend to language by placing mind and body within local, situational productions of meaning. Cultural psychology, for example, demonstrates that “cultural traditions and social practices regulate, express, and transform the human psyche” (Shweder, 1991, p. 73), and feminist theory shows that matters of personal distress are intertwined with political struggle and oppression (Hanisch, 1970). The *lived* body is relatedly entangled in shared systems of meaning, known as the “*social* body,” as well as controlling, hegemonic forces of power, known as the “*body politic*” (Scheper-Hughes and Lock, 1986). For example, our local social worlds may define what constitutes illness and disability, as already noted above with regard to contested illnesses. Moreover, some illnesses may actually be a product of social conflict; anthropologist Arthur Kleinman used the term *sickness* to denote disease “in relation to macrosocial (economic, political, institutional) forces...seeing it as a reflection of political oppression, economic deprivation, and other social sources of human misery” (p. 6).

By studying dominant cultural discourses around cancer and their engagement in people’s expressions of themselves, we can gain entry into some of the larger contexts of social and political meanings and practices. What these contextual considerations do for us is draw connections between language (which Barthes saw as empty of substance and lacking any reference to life), the felt experiences of an individual’s lived body, and the concrete and everyday interactions that make up what is known in critical circles of illness studies as the “lived relations” between people (e.g., Chouinard, 1994; Good, 1994; Scheper-Hughes and Lock, 1986).

3. Narrative Expressions of Illness

Studies of illness expressions often portray narrative as one of the most quintessential modes of expressing lived bodies and lived relations (Charon, 2008; Frank, 1995; Good, 1994; Kleinman, 1988). Narratives produce what Paul Ricoeur (1988) called a “virtual experience of being-in-the-world” (p. 100)—an imaginative reconstruction of lived experiences¹¹. Through people’s stories the personal and social contexts of meaning and experience are not only made available but are placed front and centre. According to Arthur Frank (1995), our bodies become ineffable in illness and only through stories can we restore a sense of intelligibility (p. 2). Furthermore, narratives help to place the events of illness within a larger life story (Freeman, 2010a, 2010b), relating the past life before diagnosis, the present life of treatment, and the imagined future life of recovery or death.

These attempts to conceptualize and narrativize our suffering are also intersubjective in that they depend on cultural forms of meaning-making (e.g., common tropes like journeys and battles) and they are co-constructed by our stories’ many characters, co-authors, and audiences (Good, p. 158). Intersubjectivity crosses two axes: the sharedness of everyday lived relations, or what existential psychologist Adrian van Kaam (1966) described as “horizontal coexistence”; and the effects of shared histories on the present, or “vertical coexistence” (p. 29). Through the study of stories we may come to appreciate both horizontal and vertical coexistence, what we may think of, respectively, as lived relations within the present and lived relations with the past.

Personal narratives of cancer are becoming increasingly popular and a means of drawing attention to authors’ moral, political, and existential issues. Numerous published narratives of young adult cancers have been released in North America in recent years, including

¹¹ Ricoeur applied this understanding to fictional and historical narratives alike, both involving creativity in putting events into plots.

autobiographies (e.g., Corrigan, 2008; Handler, 1996; Zammett, 2005) and combined narratives from different patients or family members (e.g., Karr, 2007; Middlemiss, 2008; Rosenthal, 2009). Print media is not the only narrative mode used by young adults. Advocacy groups like Young Adult Cancer Canada invite members to post profiles on their website. The Huffington Post developed a website called “Generation Why”¹² to share young adults’ stories of cancer through videos, blogs, and digital images.

Narrative as a particular form of expression can be delineated in a wide range of ways. Medical sociologist Catherine Riessman (2008) wrote that narratives can be defined more rigidly as a specific unit of speech with identifiable elements¹³, or more loosely as any account of self regardless of structure, including “evolving dialogues” or “brief fragments” of talk (p. 136). Riessman herself carried a relatively flexible definition of narrative, which I employ in my analyses: “a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story” (p. 3). Riessman saw storytelling as “only one form of communication” distinguishable from debate, argumentation, essay, report, and others.

Narratives may also be seen either as synonymous to stories or as a subspecies of stories (Riessman, p. 6-7). With regard to the former position, a variety of narrative scholars treat the terms ‘story’ and ‘narrative’ interchangeably as causally connected events through an evolving plot (e.g., Randall and McKim, 2008; Ricoeur, 1984; Riessman, 2008; Sarbin, 1986). The latter position asserts that stories follow a sequence of events over time, while narratives take the step further to link events into a plot (Forster, 1963/2000, p. 45; White, 1981, p. 5-16). Thus, for

¹² A play on “Generation Y,” a term often used to refer to the current cohort of people in their 20s and 30s.

¹³ For example, sociolinguist William Labov determined specific ingredients to a “fully formed” narrative: an abstract or main point, an orientation to a past scenario, evaluation of the event, resolution of conflict, and a coda returning to the present (as cited in Riessman, 2008, p. 84).

example, narratives are distinguished from annals or chronicles possessing only a temporal chain of events (White, 1981). Within this latter framework, a basic chronology of hospital appointments, treatment times, and follow-up appointments may be seen a story absent of narrativity, while an account in which remission is shown to come about through an effective and timely treatment regime could be considered a *bone fide* narrative.

I lie somewhere between the two positions. I would not reify possible differences between plotless stories and emplotted narratives because plots are not always stable and coherent; they have the potential to leave aporias of meaning and harbour disruptions or inconsistencies (Ricoeur, 1984, p. 73), carrying within them what could be called ‘plot holes’ ripe for deconstruction. Illness narratives often involve phases of disintegration as well as coherence, exposing vulnerabilities to chaos and uncertainty (Rimmon-Kenan, 2002). On the other hand, some stories that initially seem to lack plot may, in a truncated or implicit way, express causation; for instance, some health researchers have suggested that chronological medical charts can be seen as compacted narrative renderings of patients’ longer and more complex stories (Charon, 2008, p. 137-146; Kleinman, 1988, p. 17). Thus, the lines between narratives and other kinds of stories or accounts are permeable due to the fragility of plots.

4. Narratives and Practices

Narratives may be said to have “mimetic relations” with people’s lived experiences and everyday practices (Ricoeur, 1984, p. 32). According to Paul Ricoeur, narratives and practices/experiences are dialectically related. On the one hand, we tend to live in a storied form of time where our experiences flow from one moment to the next, and in some circumstances we implicitly act out culturally familiar narratives and tropes (e.g., Carr, 1986, p. 45-51; Ricoeur, 1984, p. 74-75; Sarbin, 1986, p. 8; Turner, 1981, p. 149-152). On the other hand, our narratives

are often purposeful productions, what Jean-Paul Sartre (1960/1968) understood as “praxis,” heading toward satisfaction of situational needs and desires (p. 5). In other words, narrative plots can have practical and moral utility, received and used by audiences (Ricoeur, 1984, p. 70-71); the storyteller, wrote philosopher Walter Benjamin (1955/2000), “has counsel for his readers,” whether it is a universal proverb, friendly suggestion, or caring advice (p. 47). Furthermore, people try to work out the challenges and circumstances of life not only for their listeners but also for themselves. Aside from a didactic process, telling stories may also cultivate a reflective process of “autobiographical reasoning” (e.g., Baddeley and Singer, 2007; Habermas and Bluck, 2000), that is, thinking through problems of action and understanding by narrating them.

Plots of illness narratives often initiate “mimesis-praxeos,” that is, applications or imitations in practices (Ricoeur, 1984, p. 70). According to physician and literary theorist Rita Charon (2006), plots are the “engine” not only of illness narratives but also clinical practice, in which attempts are made to emplot or to explain specific events within patients’ lives in order to direct therapeutic action (p. 48-50). Medical anthropologist Cheryl Mattingly (1998) noted that, in medical contexts, clinical practices prime patients for storying their experiences: “Many kinds of social actions (including many therapeutic interactions) are organized and shaped by actors so that they take on narrative form” (p. 19). Both clinicians and patients try to make manifest an “untold story” (p. 46), they “want something to happen” throughout the course of treatment, in particular, a “milestone, even a transformative moment” that moves the lived story along “a path from illness to rehabilitation” (Mattingly, p. 6).

The same is true outside of clinical practice, as some young adult support organizations *imitate* quest-like narratives in their services, like the Montreal-based VOBBC who provide “Vo-pak” backpacks with information for ‘navigating’ through cancer care, or the rafting

adventures of Calgary-based Survive and Thrive Expeditions meant to foster reflection and exploration. Our stories and our actions thereby shape one another, a dialectic that for Jean-Paul Sartre (1960/1968) meant people are both creators and products of their expressions¹⁴.

5. Prototypical Plots or Illness Narrative Forms

Individual stories imitate other stories as well, what we might call “prototypical plots” (Good, 1994) that are collectively shared and socially legitimated stories, lent credibility because of their familiarity (Todorov, 1968/1981, p. 18). They provide cultural forms for telling stories, creating mythic patterns of the world in revealing, though selective, ways. Here we may understand ‘myth’ as literary theorist Anne Hunsaker-Hawkins (1993) did, as both an “illusion of fiction” and a “more profound truth” (p. 19); though imaginative constructions of experience, the powerful imagery of mythic plots may communicate intense realities of chronic illness. I want to emphasize this point because, as I show throughout my analyses, the young adults’ stories heavily relied upon mythic plots, figures, and explanations of suffering to communicate their needs and desires.

What we now understand as prototypical plots has a long historical progression of loosening restrictions and welcome inclusions into an ever-widening taxonomy. In the *Poetics* (1987), the classical Greek scholar Aristotle listed four dominant plots: tragedies, poetry, comedies, and epics, the last of which may include battle stories (p. 4-7). According to Paul Ricoeur (1985), this taxonomy diversified with the emergence of the modern novel, its relative emphasis on character development and private experience over the evolution of events into a tragic or comic ending (p. 9-10). From there literary types proliferated exponentially, including

¹⁴ In his dialectical language, Sartre described this as a double relation between expressions and being: our being is already “signified” by other “signifying” persons, expressions, etc., but we are also signifying persons who transform how our being is signified (p. 165-166).

those intended to resist traditional modes of storytelling such as “epistolary” (i.e., letters and documents) and “carnivalistic” (i.e., polyphonic) novels (Ricoeur, 1985, p. 10-14, p. 96-97).

For its part in this history, non-fictional life writing became much more popular in the 18th century, taking its cue from some of the more ‘life-like’ structures of novels to explore personal and social issues in individuals’ lives (Kadar, 1992, p. 3-6). This form of non-fictional narration has seen a recent boom, demonstrated by the list of sixty kinds (p. 253-286) provided by Smith and Watson (2001/2010). Illness narratives, or “pathographies” (Couser, 1997; Hunsaker-Hawkins, 1993) emerged in the 20th century as a sub-genre of life writing, when illness started disappearing from everyday life and becoming both more institutionalized and more manageable by modern medical advancements (Hunsaker-Hawkins, 1993, p. 11)¹⁵. This now burgeoning narrative form centres around an experience of acute, chronic, or terminal illness.

Illness narratives are often “cautionary parables” in the sense that they “offer us a disquieting glimpse of what it is like to live in the absence of order and coherence” (Hunsaker-Hawkins, 1993, p. 2-3). They forewarn others about a number of contemporary health issues and debates: the spiritual or existential trials encountered in illness; the depersonalization of modern medicine, on the one hand, and its perceivably miraculous treatments on the other; the power of the mind to heal or destroy oneself; or some other testimony to illness experience (Hunsaker-Hawkins, 1993, p. 3-4).

¹⁵ ‘Pathography’ is a problematic term for a couple reasons. For one, it often refers only to published stories of illness (see e.g., Couser, 1997, p. 4; Hunsaker-Hawkins, 1993, p. 2-3), while I use it more freely as a reference to any story of illness. Second, Couser (who coined the term) later regretted that coinage, recognizing that many who write about illness challenge medical constructions of illness and resist some of the negative connotations of pathologizing language (Couser, 2005). He thereby concluded that it may be better to label them “anti-pathography” narratives, or perhaps not even as “pathographies” at all (p. 143). For these reasons, I will stick to the term I am most comfortable using, i.e., illness narratives.

Though they stand out in this regard, illness narratives overlap with a variety of other narrative forms—not surprising since they usually do not abstract the disease from its effects on and connections with other areas of personal and social life. Arthur Frank (1995) noted that illness stories tend to resemble autobiographies of spiritual conversion, gender identity stories, and survivor narratives (e.g., of war), as they all involve serious disruption and reclamation of selfhood (p. 69). As an example, in her story of cancer in middle age newspaper columnist Kelly Corrigan (2008) interwove the evolving plot of her illness with that of a familial memoir, recounting earlier life episodes reflecting her relationship with her Irish-American father.

Other forms of life writing from Smith's and Watson's (2001/2010) collection may be relatable to illness stories: testimonies of suffering and trauma; autothanatographies (i.e., self-stories about dying); personal memoirs, which like Corrigan's *The middle place* may include episodes of illness in and amongst broader life stories; *bildungsroman* or coming of age stories, if we think specifically of adolescent and young adult illness narratives; biomythographies placing oneself within mythic conceptions of the world; and internet blogs, an online form used by many of my research participants, usually mixing a personal journal, chronicle of diagnosis and treatment, and reflective essay about how to perceive illness. This list, which could be extended much further, shows that prototypical plots are neither clearly nor distinctly separable from one another. Rather, they may blend into and build off one another, producing complex narratives that cannot easily be categorized as one kind of story.

6. Narrative Moments of Meaning

As different plots often intermingle and cohabit a single narrative, the meanings constructed in stories are perhaps best understood as '*moments of meaning*.' Because narrative forms are malleable and permeable, we should not see emplotment as forsaking the flooded river

of lived experiences in favour of a clean, formal story. Rather, with shielding sandbags of cultural meanings and individual innovative techniques, emplotment redirects the flows of life into more manageable streams. Emplotment orders experiences into logical and temporal successions (Ricoeur, 1984, p. 39), but they are “never the simple triumph of ‘order’” (p. 73). Rather, included in plots are narrative “dramas” of tensions, disruptions, and negotiations (Mattingly, p. 154; Turner, 1981, 1986).

Stories may sometimes contain “redemption” (McAdams, 2006, p. 232) or “restitution” (Frank, 1995, p. 77), in which conflict is resolved, health restored, and liminal phases overcome, but these moves toward harmony are not always guaranteed or desired. Circumstances may change over time as people try to write endings to their stories, producing later ‘hindsight’ that, according to narrative psychologist Mark P. Freeman (2010b), require rewriting earlier life events. In the throes of shock some newly diagnosed patients may see cancer as a daunting and terrifying thing, yet after an uncomplicated treatment and good prognosis they may speak of their illness as a minor health issue. Over time people may modify their stories again and again depending on their health status, moods, purposes, and audiences at the time.

Talking about past experiences is always a creative task of remembering earlier felt emotions and meanings as well as producing new ones—often as a result of later events (Frank, 1995; Freeman, 2010b). Instead of enduring states, assertions, or “global meanings” (Park and Folkman, 1997)—it seems more fitting to conceive narrative meanings as momentary productions in situational contexts, open to reevaluation, revision, and opposition. This does not mean narrative meanings are inherently false or untrustworthy. As Arthur Frank (1995) has argued, narratives share insights into “not only what *was* experienced, but equally what *becomes*

experience in the telling and its reception” (p. 22; original text). In other words, we may catch glimpses of past experiences along with present interpretations and future expectations.

7. Narrative Moments of Being

A correlated function to meaning-making in narrative is self-making, producing what is referred to as “narrative identities” (Rimmon-Kenan, 2002) or “self-stories” (Frank, 1995, p. 56). Vast is the theoretical commentary on the concept of ‘self’ (De Munck, 2000), ranging from rationalist theories of a singular entity held constant over time (e.g., Descartes’ dictum, “I think, therefore I am”), to more dialogical theories of a self formed through social interaction and internalized self-talk (e.g., Shweder, 1991), to post-structural and post-modern theories of ‘decentered’ (e.g., Heidt, 1991), “protean” (Lifton, 1993) or “distributed” (Bruner, 1990) selves across a spread of situations, roles, and practices¹⁶. Some scholars have historicized different cultural perceptions of ‘self’ in Western societies, juxtaposing an earlier “*ancien regime* of identity”—in which selves were taken as more fluid and traversable across different social spaces such as race, class, and age—with an emerging regime over the last few centuries of a more individualized, fixed, and static self (Wahrman, 2004, p. 275; see also Mauss, 1985, p. 19-22).

The vagary behaviours of cancer cells and the situational interpretations of people living with chronic illness leads me to some skepticism about an enduring self. My ontology of self may be plotted somewhere between dialogical and post-structural theories and borrows from both existentialist and deconstructionist schools of phenomenology. Though admittedly odd bedfellows, the two schools share a blanket assertion that selves have temporary or indeterminate

¹⁶ At its most extreme, this position asserts that no self truly exists, that all we have are our temporary roles and performances, that the self is but an empty symbol or imaginary concept and around its borders we feebly try to appropriate it (De Munck, 2000).

centres (e.g., Charne, p. 8; Heidt, 1991; Park, 2006)¹⁷. Our self-stories and “self-readings” are situational productions of being, and may or may not be synthesized into a singular Self as they are continually under personal and social negotiation (Randall and McKim, 2008, p. 99-102).

What results is not a static self, or even a self that can be understood as given, but rather a tentative self (Randall and McKim, p. 17), what Virginia Woolf described as fleeting “*moments of being*” carried along a sea of “*moments of non-being*” (Woolf, 1938/1985, p. 78-79)¹⁸.

Narrated attempts to construct a unified self sometimes fail or are so abstracted from the changing currents of lived experience as to be seen as mere fictions (Charne, p. 13; Heidt, 1991; Olney, 1998, p. 24-25). Drawing on deconstructionism, literary theorist Edward Heidt (1991) referred to this as an act of “violence”: “The violence occurs when an autobiographer forces the construction of a system, a narrative, to represent the essence of the particular experience or even the life itself” (p. 222). This imposition is done at a time when some aspects of self are remembered and introduced into the narrative, while other aspects are forgotten, ignored, or left out; thus, the narrated self is an incomplete, edited, and perhaps even incorrect representation of the author’s being-in-the-world. Liminal experiences like illness may elude assertions of being and narratives of coherence.

¹⁷ It may be a hard sell to attempt a consistent theory of selfhood using two typically opposed traditions of philosophy. However, I consider them as complementary in their treatment of mind and language; in different ways they criticize the self-sameness of identity, favouring ways of exposing gaps of being. For example, in *Deconstruction and the remainders of phenomenology*, literary theorist and philosopher Tilottama Rajan (2002) argued that the legacy of Sartre “finds in consciousness the same difference and nonidentity that deconstruction later finds in language” (p. 60).

¹⁸ I take some liberties with Woolf’s concept of “non-being,” which she defined as the prosaic and unremarked “cotton wool of daily life” (p. 80-81). I take a cue, however, from her description of moments of being—as a “revelation of some order,” sudden perceptions that “behind the cotton wool is hidden a pattern” (p. 80-81)—in concluding that moments of non-being can be similarly profound illuminations of dis-ordered, un-patterned life, of selves spread across untethered plains. In other words, we may be sometimes gripped by the elusiveness of our own selfhood. Furthermore, moments of being are somewhat dependent upon non-being, for patterns to our identity may only be knitted out of the seemingly unraveled backdrop of scattered situations, roles and practices we engage in on a day-to-day basis.

On the other hand, narrating does not always coat the colourful provinces of consciousness with a thieving frost. Heidt admits, “The violence is in the synecdochic, idealizing self-invention itself, not so much in the metaphoric, metonymic remembering and re-telling” (p. 222). The dangers of misrepresentation lie in essentializing narratives, where ephemeral moments are taken for hard steel monuments of Being. Not all narratives strive for this dubious ideal; they may be great communicators of struggle, ironic references to absurd circumstances, potent expressions of uncertainties, and even confessions of the impossibility of order. As social scientists Hyvarinen, Hyden, Sarrenheimo, and Tamboukou (2010) have argued, narratives may sometimes be less indicative of an allegedly “complete and intact self” and more of a “creative study of one’s history and its complexities” (p. 7). Stories may be exploratory, what Victor Turner (1986) saw as expressing a “subjunctive mood,” namely, “the mood of maybe, might be, as if, hypothesis, fantasy, conjecture, desire” (p. 42).

Furthermore, narratives are not solely for the purpose of representing pre-narrative selves. As performances, our stories often construct what could be called “practical identities” through “practical reasoning,” directing our self-images according to the specific demands of current circumstances and audiences (e.g., MacKenzie, 2008; Velleman, 2006). Literary theorist Shlomith Rimmon-Kenan (2002) stated that, “The act of narration is, at least partly, a response to the needs of the present, as distinct from an attempt at a faithful representation of the past” (p. 15). Illness narratives construct a provisional and pragmatic order that may (or may not) satisfy such diverse needs as reducing pain or isolation, releasing frustration, envisioning hope, recruiting ‘witnesses,’ or seeking recognition.

Just as we are limited in making conclusions about objective reality or thought process from expressive meanings, narrated selves may or may not correspond to a body-self of lived

experience or an enduring, mental self independent of the body. My attention to narrative identities is in the capacity of recognizing *moments of being* and *non-being*, trying to understand for what purpose they may be constructed, and withholding claims about the self beyond the reach of situated expressions.

8. Narrative-Audience Relations

As an audience to young adults' stories, I am implicated in what was said and why. The audiences of stories have a chance to enter the lives of others, influence moments of meaning and being in their responses, and perhaps develop affinity and kinship with narrators. According to sociologist Arthur Frank (1995), those who listen to the stories of patients can become "witnesses," and "a particular quality of the word witness is its movement of outward concentric circles. When someone receives the testimony of another, that person becomes a witness, and so on" (p. 142). The camaraderie built from storytelling and listening can lead to social mobilization and change—for example, advocacy and awareness campaigns—making illness narratives powerful tools for rallying support of certain causes.

The social impact of illness stories is not without its politicking. Narrative 'truths' are given moral and political status, as impetuses for action (Ricoeur, 1984, p. 70-71; Riessman, 2008, p. 8). Literary theorist Sidonie Smith (1993) argued that narratives often serve as "manifestos," public declarations of evidence that the body-self has incurred injuries from a sovereign¹⁹ (p. 156-157). In this way, illness narratives can be used to serve or to resist certain hegemonic interests. Audiences may be deceived (intentionally or not), their glances diverted from hidden or alternative truths. For instance, the critical documentary *Pink ribbons, Inc.* (2011) illuminates some of the corporate use of the breast cancer symbol as a marketing ploy. In

¹⁹ This could be a verbal attack against cancer itself (seen as an imperialistic entity), against the institution of biomedicine, against a society's stigmatizing fear of the disease, or other perceived adversaries.

addition, the contested grounds of alternative medicine is often defended through anecdotes of cancer recovery, with the tacit suggestion that if it works for one it works for all.

Narrators use a number of rhetorical devices for their purposes (Riessman, p. 8; Smith, 1993, p. 154-156). For instance, they may position themselves as a universal subject, a member of humanity in general (instead of accounting for race, class, wealth, or social location), and thus invite readers to think, “If they can do it, so can I.” Such voices can empower listeners, like other patients, to pursue similar treatments, but they can also hide structural factors like wealth and healthcare access that get in the way of all patients being treated as equal. Narrators may alternatively situate their identities within certain groups, such as women of colour with breast cancer. While they may bring to light differences in illness experience, some audiences may find these accounts not as relevant for themselves and thus are left unmotivated or dissuaded (Smith, p. 155-156).

Other narrative strategies are used to draw people into stories, get them emotionally invested, perhaps even entertain them (Riessman, p. 8). People may construct a drama of pain and personal struggle (e.g., Middlebrook, 1998), use dark humour and comic relief (e.g., Handler, 1996; Radner, 2009), or draw parallels with larger myths and epics (e.g., Lerner, 1991). One young man wrote a “comedy of terrors” about leukemia and poked fun at the bureaucratic rituals of the healthcare system (Handler, 1996), while another glamour girl jokingly wrote that she was thrilled to lose weight as a result of chemotherapy (Zammett, 2005). For their part, audiences may expect certain kinds of illness stories to be told—particularly those with healed bodies and happy endings (Rimmon-Kenan, 2002)—and people may modify their stories and strategies to fit within their audiences’ expectations.

9. Conclusion: The ‘Truths’ of Illness Narratives

It is important to consider both the values and the limits of attending to stories. In the words of cultural psychologist Jerome Bruner (1986) the “life as told” and the “life as experienced” are connected but they suffer “inevitable gaps” (p. 6-7). Thus, we face a question about the *truth* of narratives: if they do not wholly represent experiences, then how can we treat them as true? The Personal Narratives Group (1989) address this issue in a helpful way, by redefining the notion of ‘truth’:

When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they *are* revealing truths. These truths don’t reveal the past ‘as it actually was,’ aspiring to a standard of objectivity. They give us instead the truths of our experiences... Unlike the reassuring Truth of the scientific ideal, the truths of personal narratives are neither open to proof nor self-evident (p. 261; original text).

Narratives may not adequately ‘capture’ individuals’ experiences, but they express local truths that are their own. Recognizing that experience and narrative are somewhat connected enables us to “witness” and “honour” storytellers’ distress on their own terms (Frank, 1995; Charon, 2008). However, acknowledging that this connection is always tenuous, that meaning and being are always flimsy, opens the door to critically questioning stories, especially around what *else* may be a driving force. *Cultural discourses* are among many possibly relevant forces to narrative construction, but they are of particular importance to thinking through the politics and poetics of narratives. The final section on conceptual tools reviews how cultural discourses may be intertwined with lived experiences and narrative expressions of illness.

C) Cultural Discourses as Illness Narrative Environments

Moments of meaning and ***moments of being*** are not simply productions; they are struggles, in the sense that people come up against “limited possibilities, finite abilities and scarce resources,” and are in constant jeopardy of being “thwarted, conflicted and thrown by

contingency and circumstance” (Jackson, 2005, p. xiii-xiv). Among many other delimiting forces within each person’s local world are dominant ways of thinking about and narrating illness.

These prevalent cultural forms can sometimes become prescriptive or ideological, the default and normalized modes of expression, overshadowing alternative voices and perspectives. However, we cannot help but be participants in discourses.

I take it that people telling stories of cancer work within culturally constituted *spaces of experience* and *horizons of expectation*, what may be called *narrative environments*. Within the frames of narrative environments people try to find stories or plots that make sense in their lives, and in the process may reinforce, clash against, or cross these borders. There are two-way interactions between experiences, narratives, and discourses: a) individual narratives reinforce discourses as they depend upon a language created outside/before personal experiences, and b) narratives add to the textures of discourses by creating new constellations of experience through creative metaphors and innovative plots. As people participate in and interpret discourses, meaning and being are negotiated and indeterminately formed into narrative productions.

1. Enabling and Disabling Narrative Environments

People often rely upon precedent symbolizations of illness to make sense of themselves and their lives. Referred to as dominant cultural discourses or “master narratives” (Mishler, 1995), “normalizing ideologies” (Becker, 1997), or “cultural myths” (Hunsaker-Hawkins, 1993), these cultural precedents propose that subjects should take on certain identities and life events should follow certain paths. According to disability studies scholar Susan Whyte (1995), “discourses are ways of objectifying situations, issues, values, persons, and relationships”; in their expression “a message is conveyed” (p. 268). For example, within North America aging cancer patients are perceived to be on terminal trajectories of “decline,” a quick track toward

bodily failure, social disconnection, and imminent death (Hammond et al., 2012; Sinding and Gray, 2005).

Perhaps younger cancer patients are influenced more by discourses of ‘recovery’ than discourses of decline. Rimmon-Kenan (2002) recapped recovery discourses thus: “in Western society, the first commandment of illness seems to be ‘get well!’ ...and if this fails—at least conceal disruption under a semblance of continuity and/or victory” (p. 14). Kathy Charmaz (1992) saw this as a moral imperative among patients who felt they “deserved” to get better, unwilling to accept the chronicity, perhaps even the terminality, of their illness (p. 15). Whether acute or chronic, illness is objectified as temporary forms of being-in-the-world from which we return. Expectations of recovery are encouraged in part by what Arthur Frank called modern medicine’s “telos of cure”—defining itself more often by the ability to end disease than the ability to provide supportive and holistic care (p. 83). Representing some of the difficulties with dominant discourses, medical discourses of recovery and cure do not always fit well with experiences of chronic or terminal illness among all ages (Charmaz, p. 42-43; Frank, p. 83).

The influence of discourse does not just come later, in times of retrospection or reflection. Our very experiences of illness may be guided by shared narratives of how illness *is* and how it *should* be. As already noted, Mattingly (1998) saw that recovering patients often experienced treatments as recovery narratives rooted within particular cultural understandings of medicine. Our perceptions prior to telling stories are to some extent ‘conditioned’ by cultural understandings of self and its relation to the world (e.g., see Nisbett, 2003). Thus, the relationships between narratives and experiences are mediated by pervasive influences of cultural systems of meaning.

As cultural precedents, dominant discourses exist as “*narrative environments*” prior to people’s personal objectifications of experience (Randall and McKim, 2008). Discourses that influence people’s thinking about their lives provide both “*spaces of experience*” and “*horizons of expectation*” for understanding present circumstances and imagining future possibilities (Ricoeur, 1985, p. 208-209). They fall under what Sartre (1960/1968) defined as the “practico-inerte,” the pre-existing (though not static) social and material conditions that affect people’s activities and meanings by simply being there (p. 173). More fundamentally, discourses may constitute people as ‘subjects,’ that is, make it possible for them to see themselves as having certain identities and being part of larger intelligible worlds (e.g., Foucault, 1978).

This is both a bane and a boon. Discourses may be used for ideological purposes, legitimating only a few identities and meanings and foreclosing many others. Critical perspectives on discourses challenge the ways in which narrative environments may restrict the range of ways of being-in-the-world (Roberge, 2011). For example, literary theorist Carolyn Heilbrun (1989) outlined how women wishing to participate in public stories are often discursively relegated to the ‘private’ sphere of home life, while historian Michel Foucault (1978) saw normalizing categorizations of sexual practices within a plethora of scientific discourses beginning in the 19th century (p. 58). In these examples, discursive constructions of gender and sexual identities not only create but also control the subjects so labeled.

However, dominant discourses are not necessarily of the ‘Big Brother’ variety in George Orwell’s *1984*, tyrannically stifling human freedom and serving figuratively as “a boot stamping on a human face – forever” (1949/2004, p. 334). Narrative environments may open up ways of understanding for those in times of crisis. In fact, as expressions depend upon the language and signs we have been socialized into, we cannot help but to use the narrative environments

available to us in our daily struggles. Narratives of illness, in particular, construct selves and meanings using the “building blocks of metaphor, image, archetype, and myth” inherited from past and present discourses (Hunsaker-Hawkins, 1993, p. 18). Thinking about how we may break free from oppressive ideologies, Paul Ricoeur wrote, “There are no other paths, in effect, for carrying out our interest in emancipation than by incarnating it within cultural acquisitions” (as cited in Roberge, 2011, p. 5).

In this way, discourses may be restrictive but they may also be ‘productive’; they do not simply hedge people’s efforts to understand their worlds, but make possible construction of selves and meanings in socially recognizable and practically useful ways—including critique of those very discourses (Becker, 1997; Butler, 2004; Foucault, 1990). Discourses of decline, for instance, *enable* aging cancer patients to talk about suffering, loss, and death, while *disabling* recognition for doing well or suffering little during these experiences. Discourses of recovery or “progress,” on the other hand, marginalize indefinite experiences of liminality while lending credence to talk of illness as a thing of the past (Hammond et al., 2012).

2. The Potential Formlessness of Suffering

Despite their power to constitute subjects, dominant discourses are not necessarily bandages for bodies “leaking” meaning (Devaney, 2012). Customary storylines do not always offer fitting plots for individual cases. In some circumstances, according to Cheryl Mattingly, people cannot story their illness because “lived experience seems to be driven by no form other than brute sequence,” that is, it lacks emplotment (p. 47). These moments can occur, for instance, when treatments are not working, or when clinicians dismiss patients’ attempts to story their experiences in a certain way (Mattingly, p. 129). In any case, the constitutive function of discourses can break down in local situations.

Many cancer patients express feeling life has lost its meaning (e.g., Bolmsjö, 2000, 2002; Jacobsen, 2006; Morita et al., 1999). Patients' expressions of meaninglessness and of plotless "brute sequences" of experience suggest that some forms of 'unhomelike' being may toe the borders of intelligibility within given cultural discourses (see e.g., Becker, 1997).

Anthropologists Janice Jenkins and Martha Valiente (1994) noted a great deal of ambiguity in how Salvadoran women talked about their symptoms of *nervios*, meaning "nerves," a common idiom of distress involving, among others, a sudden feeling of intense heat or *el calor* in various parts of one's body (p. 168). Specifically, some found it difficult to articulate their experiences even though *el calor* was a familiar and readily available concept, and some used the term literally while others used it metaphorically. Having access to well-known cultural categories, like *nervios*, does not guarantee people will be easily able to story their felt encounters with illness.

Mattingly was quick to point out that "formlessness is not so much a description of the structure of everyday life as a depiction of despair" (p. 47). When dominant discourses fail us or lose their hold, we may grieve over losing the ability to make experience meaningful. When people talk about a sense of 'meaninglessness,' according to literary theorist Terry Eagleton (2007), they are not referring to a lack of meaning—as narratives always carry a multitude of meanings—but a lack of direction in the face of many competing, discordant meanings that take no authority over another (p. 36-37; p. 58-59). A dominant discourse loses its authority and a host of alternative discourses contend for power. Jenkins and Valiente argued that, in fact, bodily experiences of illness contribute to the historical shifting of discourses, or the construction of new cultural meanings, when readily available meanings fail to explain them (p. 176).

3. Negotiations of Meaning and Being

Although my work hones in on *dominant* discourses, there are many other discourses operating at the same time in people's lives, leading to much more complex narratives of experience that need to be accounted for (Whyte, 1995, p. 275-280). It is important, as Whyte has argued, to "find a way of describing a dominant pattern while showing the extent to which people ignore or actively contest it" (p. 281-2) through employment, evaluation, and invention of different discourses. In this sense, the parameters making up our spaces of experience and our horizons of expectation are not necessarily clear and distinct; the variety of discourses available to people enables a multitude of voices, a polyvocality, to narratives of illness.

The links between the *lived*, *social*, and *political* bodies are relevant here. The body is a social object assigned and manipulated by cultural meanings, but it is also a social agent capable of disputing, resisting and even producing cultural meanings (Becker, 1997; Jenkins and Valiente, 1994; Lyon and Barbalet, 1994). In other words, the discourses swirling around us often require *negotiation* in episodes of acutely transformative experiences. Anthropologist Gay Becker (1997) observed that Americans who experienced infertility, stroke, chronic illness, or late-life transitions sometimes repeated and other times rejected dominant cultural assumptions about the orderliness and "rational determinism" of life (Becker, 1997, p. 6, p. 65, p. 78). She concluded that although the discourse of "everything happens for a reason"—which can also be found in my participants' narratives of young adult cancer—exerts both explanatory power and normalized pressure on individuals, people sometimes found this discourse oppressive, inadequate, or daft.

It may be that meaning and being is neither culturally determined in full nor completely derived from individual agency or creativity (Becker, p. 123; Gendlin, p. 163-164; Jenkins and

Valiente, p. 169-170). There seems to be a process of negotiation and renegotiation between personal experiences, narratives, and varying cultural discourses, especially as circumstances and needs change, and as plot twists take people's lives into new directions. This process of negotiation is possibly what Paul Ricoeur (1984) meant by "iconic augmentation," where each and every narrative reconstructs reality, taking "presignified" narrative forms and drawing new meanings and new pathways into them, making them "oversignified" (p. 77-82).

Indeed, it may be part of the human condition, as Jean-Paul Sartre (1960/1968) has defended, to continually engage in "mediations" between larger social and material forces, on the one hand, and local needs, desires, and strategies on the other (p. 58-60). Thinking of Sartre, Michael Jackson (2005) wrote that "Our humanness" is shaped by a dynamic between "circumstances over which we have little control" and "our capacity to live those circumstances in a variety of ways" (p. xi). The complexities of having cancer may be revealed in how people live with, through, and against the conditions of their existence.

4. Conclusion: Seeking (Co)Existence

In conclusion to this final section on discourses, it may be better to see biographical and existential challenges during cancer as intersubjective *negotiations* with dominant discourses, as illness is a liminal process that seems to hang definitive certainties in hiatus. These negotiations, according to Michael Jackson (2005) involve movement "between alternatives that promise more or less satisfactory solutions to the ever-changing situation at hand" (p. xii), all in the effort to create "viable forms of existence and coexistence in relation to the given potentialities of our environment" (p. xv). In this way, the *spaces of experience* and *horizons of expectation* people live within are constantly changing, expanding and contracting as people rework their boundaries. Looking at how meaning and being are negotiated with cultural discourses may

provide a glimpse into what ‘forms of (co)existence’ young adults see as ‘viable’ at a certain point in time.

Chapter Conclusion: Iterative Theory and Understanding

This chapter outlined the fundamental concepts and contexts within which my dissertation research was carried out. I have created a visual representation of how my theoretical concepts relate to one another (see Appendix A). Although I have laid the foundation, each of the following chapters expands upon or extends this foundation as it becomes pertinent. In the following two chapters, I operate within this basic framework in my evaluation of research literature on young adult cancer (ch. 2) and in my discussion of theoretical and methodological issues of representing illness experience in social scientific research (ch. 3). In the analytic chapters (chs. 4-7) I add extra concepts to my framework, highlighting how these extensions still fit within the larger set of interpretive tools.

The overarching theme of this chapter was recognition of lived diversity among young adults with cancer (in response to Kairol Rosenthal’s plea for such), meanwhile attending to the various cultural and linguistic contexts out of which that diversity is born. Though young adults may be familiar with similar discourses about their illness, they may engage with those discourses in a multitude of ways, producing an array of narrative *moments of meaning* and *moments of being*. As with the theoretical concepts, I build upon and enrich my understanding of these processes as I enter into more specific debates and discourses. It seems to me this constant movement of my framework, this ongoing incorporation of new concepts, comes out of a parallel lack of stasis I found in the young adults’ narratives, where in order to go further into the rabbit holes of their experiences I had to do some of my own digging.

Representations of Young Adulthood

“The attempt to impose upon man, a creature of growth and capable of sweetness, to ooze juicily at the last round the bearded lips of God, to attempt to impose, I say, laws and conditions appropriate to a mechanical creation, against this I raise my sword-pen”

—Anthony Burgess, *A clockwork orange*, p. 21

Introduction

The above statement starts a manuscript written by a minor character in Burgess’ (1962) dystopian novel. These few words encapsulate the book’s major theme, a debate between, on the one hand, ‘organic’ development or “growth” and, on the other, forced or “imposed” order (Dexter, 2008, p. 200-203). This issue revolves around the actions of adolescent Alex, Burgess’ sharply intelligent but sadistic anti-hero, who peruses the manuscript during a midnight raid on an isolated cottage, set in a future Britain. A bright and yet brutish young man, capable of a highly sophisticated level of thinking and scheming, Alex violated many preconceived ideas of adolescents as melodramatic and immature subjects.

Later on in the story, Alex is arrested for a few of his many criminal acts of violence and put into an experimental trial, a Pavlovian procedure of building stimulus-response associations, meant to curb recidivism and ‘make’ him into a law-abiding citizen. Conditioned to recoil from violent actions Alex is released from prison, and is subsequently caught in a form of poetic justice whereby he helplessly suffers victimization from many of the people whom he had wronged. He ends up in the hospital where his conditioning wears off and, as Burgess wanted him, he is no longer confined by the “imposed” order.

But, Burgess' desire for affirming free and uninterrupted development is betrayed by an ending to the story that seems positively deterministic. At age 18, Alex is overcome with a drastic, unexpected (for him and for his readers) personality shift; he is suddenly aware of the errors of his ways and decides to "get started on" a new "chapter beginning" (p. 148). He describes this new chapter as a powerful image, a nagging desire, a palpable future involving a wife, a son, and a home. He says to the reader, "I knew what was happening, O my brothers. I was like growing up" (p. 147).

Reacting against Pavlov, Burgess seemed to evoke a quasi-Piagetian account of development: after being left alone to make mistakes for a while (and Alex indulges in incredibly severe errors of moral judgment) children will grow into a predictable and more mature understanding on their own. Despite his history of perverse desires and aggressive actions, and despite state interventions to change him, Alex arrives on his own at a straight-laced, mainstream, and suspiciously legal project for adulthood. This last chapter was such a stark contrast to the rest of the book's tone, so difficult to believe, that in its first editions American publishers convinced Burgess to remove it (Dexter, 2008, p. 203). What Burgess saw as an acute exercise in free will, many of his audiences and critics perceived as an implausible self-correction into conformity.

A clockwork orange is an example of the difficulties in constructing images of young adults as "creatures of growth" and not "mechanical creations." Some account is needed of the social and historical contexts that surely influence young adults' lives—Alex lived in a dystopian world full of corrupt officials and hostile revolutionaries—but to what extent do we include individual creativity, choice, and negotiation? Ironically, in his attempt to accentuate the latter,

Burgess fell into a common trope of young adult desires—marriage, children, and a home of one’s own—in tension with the liberties he took in depicting adolescent life.

Similar struggles to understand young adulthood may be seen outside of fiction, in master narratives in academia, media, and public conversations. This chapter involves a critical review of some such discourses, in and outside of contexts of illness. I see myself as a less hyperbolic and grandiose version of the writer in *A clockwork orange*; I do not metaphorize my computer as a blade for cutting the hardened trunks of discourses, as though their bloomage has created an oppressive shadow from which we need to escape. However, my purpose here is to reveal how some discourses can portray young adulthood in a “mechanical” way as a collective body of subjects, minimizing diversity or variability while enhancing a sense of predictability and order. I juxtapose these images with my own understanding of young adulthood as negotiations of meaning and being within lived circumstances and narrative environments.

Young adulthood is discursively constructed for the sake of some purposeful end. Burgess wanted to show that juvenile delinquents, even of the worst kind, may come into a maturity that aligns with societal norms and expectations. Many of the discourses I review below construct young adults for a similar purpose of explaining how they come to fill their ‘roles’ in society. The first part of this chapter places discourses about *identity development* and *traditional markers of adulthood* into some social and material contexts of young adult life in North America.

The second part of the chapter entails interrogation of oncological discourses about the challenges of possibly distinct *biomedical characteristics* and *developmental tasks* within young adult cancer patients. In my review and evaluation, I am participating in these precarious naming games and co-constituting the subjects of this research as young adults. Still, I try to withhold a

strong commitment to defining young adulthood, recognizing the flaws and aporias of such an endeavour. In sum, I suggest the presence of a normalizing ideology of young adulthood, one which intersects dominant discourses of narrative identity development and young adult oncology. The following literature review is restricted to representations of young adulthood and cancer, leaving discussion of the literature on illness narratives until after the chapter's conclusion, where I make the case for a critical narrative program of study.

Understanding Young Adulthood: Some Contextual Considerations

Young Adulthood as Cultural Construction

Young adulthood has not always been a familiar developmental reference in Western societies. According to young adult literary critic Michael Cart (2011), 'young adulthood' is a term only well known to North America over the last few generations: "until 1900 we were a society with only two categories of citizens: children and adults" (p. 4). With psychologist Stanley Hall's position that there exists a third developmental category "adolescence," the 20th century started to think differently about the life span (Cart, 2011, p. 4; Rogoff, 2003, p. 172). Believing that the transition from childhood to adulthood went beyond the teen years, later psychologists started to talk about other coming of age 'stages,' like "young adulthood" (e.g., Erikson, 1968) and, more recently, "emerging adulthood" (e.g., Arnett, 2000).

While they initially may not have represented lived experiences, these discursive terms within academic have entered and continue to influence more public narratives, percolating personal and social imaginaries, shaping the way people think, experience, and act. In other words, they became reified, believed to be real and, in a way, took on a social reality in the effects they had on people's lives. For example, as developmental psychologist Erica Burman (2008) has shown, these discursive constructs have been used dogmatically toward political ends,

such as deciding certain features of individual development as “normal” and others “abnormal,” naturalizing the distinctions between by appeal to ‘biological’ underpinnings, and reinforcing their ontological status through policies and regulations (p. 117).

The discursive rise of ‘adolescence,’ and later ‘young adulthood,’ could be considered “cultural inventions” (Rogoff, 2003, 173) or ideological constructions in the sense that they developed out of interacting changes to social life and to cultural discourses of the time. For example, cultural psychologist Barbara Rogoff (2003) argued that adolescence may be a product of segregating youth from adults in North America by way of laws placing most children in schools and putting prohibitions on their work lives (p. 172). By analogy, what is referred to as ‘young adulthood’ may have started to stand out as recent historical conditions such as widened access to post-secondary education and effective birth control methods extended typified narratives of coming of age (Arnett, 2011). I do not mean to deny that biology has a place within this representation, but rather argue, as developmental psychologist Michael Cole (2006) has, that it is interlinked with culture; following the schooling examples, Cole argued that formal education alone affects cognitive development in culturally specific ways, directing the courses of memory, reasoning, self-reflection, and so on (p. 655-660), all of which are utilized as people perceive and narrate their lives.

It may be thus said that ‘young adulthood’ is not an inherent or biologically determined stage of life but a historical product of certain social, cultural, and economic shifts in industrial societies, and therefore, riding along the waves of societal change, may be interpreted and experienced in several ways. By extension, the ways in which the onset of illness may affect young adulthood may be countless. But, before we get there, we need a glance at some of the contemporary discourses of young adulthood surrounding a) narrative identity development, b)

social and material conditions of young adulthood, c) young adult meanings and ways of being, and d) emerging adulthood. I do not wish to present this as an essentializing survey of young adults nor as a desperate grasp at all the variables at play, but rather as a helpful backlight to illuminate some narrative, material, and practical environments that may shape lived experiences of those deemed young adults.

1. Narrative Identity Development

‘Young adulthood’ is a developmental term, pointing to a particular period of the life course. In trying to understand relevant contexts to young adult cancer, we cannot ignore what may be at stake in their development toward meaningful lives. One of the most important stakes in young adulthood is identity development. What that means can depend on who is asked. The well-known developmental psychologist Erik Erikson (1980) understood the development of identity as “a gradual integration of all identifications” (p. 95), that is, a synthesis of people’s conflicting desires, identities, and life experiences. Identity development is a large area of research and clinical interest. My interests lie in the smaller sub-field of narrative identity development, given my focus on narrative constructions of meaning and being.

At the time of his writings, Erikson attributed identity development primarily to adolescence. His legacy was carried forward into narrative studies of development, including his assumptions about adolescent explorations (see e.g., Baddeley and Singer, 2007; McAdams and Logan, 2004). However, as noted above, discourses about transition into adulthood have changed in the last half-century, extending the interim period beyond the teens into the twenties and even the thirties (e.g., Arnett, 2011). Erikson (1980) himself recognized that the concerns of one developmental stage were not exclusive to it and could be found in other periods of the life

course. Thus, it seems some of the discourses around adolescent identity may be appropriately applied to young adulthood.

Like Erikson, some narrativist camps construct identity development as a stage-like approach of appropriating myth, or larger cultural narratives, into one's identity. For example, childhood is seen as a "pre-mythic" time of learning to apply narrative forms to personal stories, while adolescence and young adulthood are seen as "mythic" periods of authoring an identity parallel to cultural ideals (Randall and McKim, 2008, p. 65). Clinical psychologist Dan McAdams (1993) went so far as to argue, "making life into myth is what adulthood is all about" (p. 91). It is said that after such time emerges a "post-mythic" period of reflection on one's legacy during aging, namely, whether or not one contributed to the preservation of cultural ideals (Randall and McKim, 2008, p. 65; see also Bruner, 1990, p. 80-87; McAdams, 1993, p. 67-110).

Despite a laudable sensitivity within these camps to cultural influences on identity, there is often a surprisingly universalized and moralized stance toward adult identity development. It is from these assumptions, I argue, that an ideology of young adulthood has emerged. Two thematic prescriptions ring out from this perspective: *narrative coherence* and *self-authorship*¹. To the first, stories are indicated as more "mature" if they attain standards of temporal, stylistic, causal, and thematic coherence (e.g., Baddeley and Singer, 2007; Habermas and Bluck, 2000; McLean and Pratt, 2006). McAdams (2013) asserted "continuity in experience," a synthetic unity of selfhood, as a "developmental imperative" in adulthood (p. 152). These sentiments repeat Erikson's (1980) prescriptive position on coherence, stating that "in their search for a new sense of continuity and sameness" some adolescents and young adults are "*never ready* to install lasting idols and ideals as guardians of a *final identity*" (p. 94; my emphasis). His comments are

¹ Though not always coming to the same conclusions, my analysis is indebted to theorists who have critically and insightfully engaged with narrative coherence and authorship in philosophical contexts (e.g., Carr, 1985; Ricoeur, 1984, p. 73-75, 1988, p. 169).

slightly pejorative toward less coherent identities, as failures to reach a finality or completion of self-searching.

Ambiguity or instability of identity seems to be expected to eventually subside, regardless of individual circumstances or cultural values of coherence. Narrative order is put upon a pedestal of self-knowledge and sophisticated meanings, meanwhile enduring lapses of coherence are judged as bulwarks against future maturity. It seems quite doubtful and inconsistent to recognize cultural conditions in narrative constructions of identity, yet hold fast to standards void of contextual considerations. Other perspectives within the humanities and social sciences question both the general merits and the attainability of narrative coherence, arguing that it has become an ideological imperative that does violence to the fluidity of narrative selves and meanings (e.g., Heidt, 1991; Hyvarinen et al., 2010).

Philosopher Galen Strawson (2004), for instance, criticized what he called the “ethical Narrativity thesis,” an arbitrary judgment that “diachronic” selves fitted to telling coherent narratives are inherently superior to more “episodic” selves with a weak or absent sense of a broader biography (p. 429-433). He defended more episodic selves as being non-pathological forms of living and understanding, sensitive to the vagaries of life and expediency of the present, and sometimes befitting many different life circumstances (e.g., feeling ill or in pain, carrying out quotidian tasks, telling about an isolated situation, etc.). Indeed, as I noted in the previous chapter, narrative identities may be seen as constructions more attuned to situational needs and practical concerns than to the task of synthesizing past, present, and future. It may be more appropriate in contexts of illness to minimize demands for a unified self and think of identity as more momentary occurrences—not because people with chronic illness cannot hope to tell

coherent stories, but because reader expectations for unity may be insensitive to the situational needs and wishes of those who speak about illness.

Often appended to the favouritism of narrative coherence is a perplexing fixation upon self-authorship. For example, McAdams (2013) concluded that the task of younger adults is to “become the author of your life” (p. 151). In other words, adult identities are distinguishable from more ‘juvenile’ identities by being self-directed and self-defined. In illness or other disruptive moments of life, development is perceived as taking (narrative) control of a self-in-crisis and recommitting to a unified identity (Mclean and Pratt, 2006; see also Marcia, 1973).

There are built in cultural prescriptions to this second task, a soft imperialism implicit in both of McAdam’s imperatives. His assertions would not be in good company with more critical developmental psychologists, who may see these statements as ideological constructions made to be seen as ‘natural.’ For example, Erica Burman (2008) was critical of discourses that ‘naturalized’ development as they often led to moral judgments about different developmental trajectories within or outside of a particular culture. She noted how, through selective observations, social scientists of the 19th and early 20th centuries imposed two Eurocentric associations between ontogenetic (i.e., individual) and phylogenetic (i.e., species) development: first, identifying European children with the ‘primitive’ peoples of the world, both alleged to be plagued by irrationality and magical thinking; and second, identifying European adults with the more ‘progressed’ Western cultures of *individuality*, *independence*, and *reason* (p. 13-15). Note the parallels between the alleged attributes of ‘developed’ individuals and societies, and the proposed features of ‘mature’ narratives within discourses of identity development. We are in danger of repeating the same mistaken generalizations of the past.

While I would not dispute that many younger people desire a sense of control, or at least a say, in where their lives are headed, it is not clear that this is always the case. To what extent does this make sense in situations of chronic illness where it has become quite apparent you are not driving your own life, or at least not the only hand on the wheel? Sometimes disruptive experiences elude our abilities to bestow meaning upon them, exposing what existentialist scholar Stuart Charmé (1984) saw as the “difficulties *inherent* in the narrative recording of a person’s life” (p. 9; my emphasis). Do we simply diagnose illness narratives as pathological or developmentally stalled if they show control and authorship as contestable?

Insistence upon self-authorship seems to discount the lack of certainty and control that becomes strongly apparent during serious illness. In a review of modern discourses sharing a “language of responsibility and free will” around illness and dying, historian Michael Ignatieff (1988) noted that they tend to lack a “vernacular of fate” (p. 32). He saw such discourses perpetuating assumptions that “we are the makers of our own lives” and can even be makers of our own health, ignoring that “chance and contingency and the dull determination of living all combine to push our lives into sequences we neither desire nor intend” (p. 33). Having advanced cancers in need of immediate medical intervention, submitting to agents other than oneself, and observing foreclosure of certain life possibilities, do not easily (or, perhaps, appropriately) lend themselves to narratives of self-determination. There may be other ideals toward which people strive in times of crisis, such as a ‘vernacular of fate’ or other displacement of control.

Instead of measuring upon a moral scale whether narrative ‘agency’ is expressed within people’s stories, it may be more appropriate to evaluate what psychologist Jerome Bruner (1990) called “agentivity” (p. 118-119), the range of ways agents and actions may be constructed. This broader narrative concept recognizes that the extent of agency may, “as we know from studies of

‘locus of control,’ vary from person to person, and, as we know, vary with one’s felt position within the culture” (Bruner, p. 119). Specifically, people may see themselves as participants in the drama of illness and/or externalize agency to God, those delivering cancer treatments, sometimes cancer itself. Without making normative statements, we can come to appreciate how people distribute agency among the various perceived actors within their local social worlds.

There is also the issue of co-authorship. Our stories can surely be acts of self-authorship and self-affirmation, as argued by McAdams and others (e.g., Carr, 1986, p. 93-94; Frank, 1995, p. 7), but they are often not entirely our own. They are co-authored not only by chance and contingency but also by our social encounters and narrative environments (Rogoff, 2003, p. 50; Randall and McKim, 2008, p. 32). People who are ill, whether children or adults, co-construct their stories with family and friends, health care providers, others with the same illness, and so on. It seems rather suspicious to argue that people have full sovereignty over their narratives with these many external influences operating upon them.

I am critical of the imperatives of narrative coherence and self-authorship, in particular how these constructions can constitute subjects as ‘disabled’ or ‘arrested’ or have ‘deficits.’ Anthropologists Ray McDermott and Herve Varenne (1996) described different cultural models of disability (or illness) and development, noting that the most frequent models equate development to ‘mastery’ of certain tasks—whether standardized tests like I.Q. exams or culturally relevant activities like being financially independent (p. 106-107). Discourses of narrative coherence and self-authorship repeat these ‘task-based’ models of achievement.

Emerging critical models of development argue that by defining “what to aspire to and hope for” we are creating subjects who will be inevitably deemed inferior or disabled (p.108), we are projecting “irremediable distortions of the complex persons forced to live inside” these

definitions (p. 121). In other words, task-based discourses of development are “conventions at best and political fabrications at worst” (p. 109). McDermott’s and Varenne’s solution for doing developmental research, which I take up in my own, is to study “how members of a disabled minority make sense” as well as “showing how they could have been made to look so bad in the eyes of the community and, more importantly, how to change the world enough for them to look sometimes wonderful and sometimes not, just like everyone else” (p. 114). In sum, our work should buffer against cultural idealizations imposed on and juxtaposed with those who are ill.

Development is always a risky subject, no less so with identity development, as we may easily enter into moralized positions about what is ideal. The ideology of young adulthood, as I have called it, can have a ‘productive’ side in the sense of offering guidance to young adults in crisis, but it also contains ‘irremediable distortions’ of young adults’ lives that continue to haunt influential theories of adult development (e.g., Erikson, 1980; Havighurst, 1972; Lachman, 2004; Levinson, 1986). Among many young adults with cancer are expressions of alternative ways of being and of making sense of life (e.g., Rosenthal, 2009) that are in friction with the universalist claims of some developmental psychologists (e.g., Baddeley and Singer, 2007; Habermas and Bluck, 2000; McAdams, 2013). It seems dismissive to think of narratives lacking coherent and self-authoring themes as failures to follow an ‘external’ imperative that may not be relevant to the lives being told.

I prefer to think about development in terms used by developmental psychologist Barbara Rogoff (2003) as “changing participation in sociocultural activities” (p. 50). Her definition lacks strong judgments about, for instance, where people’s identities go over the course of time. Instead of working with reified ideals of narrative development, I see a more fruitful task in observing how narratives mark changing participation, that is, how young adults’ stories engage

with, negotiate, and contribute to the narrative environments within which they are told. This approach recognizes the multiple ways in which individual stories validate and/or resist the allures of the above ideology. We need a suspension of judgment over the inherent value of narrative coherence and self-authorship, and instead respectfully listen to how young adult identities and agentivity are constructed within their own narratives. We may gain clues toward this end by looking at some of the significant conditions under which young adults lives are told.

2. Some Social and Material Conditions

Part of the work of understanding young adults' identities is placing them within certain shared socio-historical circumstances of their construction. Sometimes people refer to a "generation" to denote a common response to shared conditions among an age group of a specific time period (see e.g., Savage, Collins-Mayo, Mayo, and Cray, 2006). Categorizing age cohorts into generations was popularized in the 20th century industrialized world, and broke down the century into the kickstarting GI Generation that lived through the First World War; the Silent Generation that suffered the traumas of the Great Depression and World War II; the post-war Boomer Generation who found new prosperity and affluence, and used it to bring about a variety of countercultural and civil movements; and Generation X known for its "baby bust" and "accelerated culture" (Coupland, 1991; Savage et al., 2006; Young-Eisendrath, 2009).

"Generation Y" is said to come on the heels of the new millennium, representing today's young adults and carrying some important distinguishing characteristics from previous generations². One of the most commonly reported observations is their peculiar upbringing. According to psychotherapist Polly Young-Eisendrath (2009), dominant North American parenting practices are typically preoccupied with fostering a form of self-confidence in children.

² As with the other generational labels, no real consistent year is used to delineate who is and is not a member of Generation Y. Sufficed to say that although the most commonly suggested generational starting line is in the 1980s, it seems to be quite arbitrary where the chalk is drawn.

This confidence is cultivated by a socialized belief in one's superiority among peers and a dwelling attention on one's self-image, in sum an intensely individualistic perception of reality (p. 21). Children are supposedly taught they can be anything and encouraged to see the future as limitless possibilities (Henig, 2010; Henig and Henig, 2012; Twenge, 2006; Young-Eisendrath, 2009). Generation Y is sometimes given the alias "Generation Me" due to their allegedly incessant focus on themselves (Twenge, 2006; Young-Eisendrath, 2009, p. 47). This may be one way the myth of self-authorship is embodied in praxis.

I am somewhat skeptical of the language of 'generations,' for two primary reasons: first, they tend to be created, used, and studied within North America specifically yet often uncritically applied across different regions of the world; second, they are meant to represent popular trends, attitudes, and practices, and thus rarely account for varying or alternative characteristics however common they may be. The first limitation is not a deal breaker since my research was carried out in Canada, but in combination with the second the term "Generation Y" comes close to losing sight of the complexity of young adult lives I have tried to bring to light.

In terms of some of the material conditions young adults face today, some social scientists and journalists report that the current global recession economy and its effects on local economies has made it much more difficult to acquire financial stability and independence. Accounting for inflation, recent articles in the *Globe and Mail*, *The Walrus*, *New York Times*, and *Maclean's Magazine* compared young adults of the new millennium and of the mid- to late-20th century, and they found much higher tuition fees, higher mortgages, higher unemployment and lower minimum wages now than 30 years ago (Carrick, 2013; Coates, 2012; Henig, 2010; Lunau, 2012). Many teens are encouraged into "mass participation" of post-secondary education, creating a balloon of graduates unable to be fit into the available skilled positions (Coates, 2012).

The majority of university and college graduates today have too few employment opportunities and too high qualifications for the current job market (Coates, 2012; Lunau, 2012).

All of this plays into the work trends of unemployment and underemployment, as well the home trends of struggling to maintain financial stability, paying off student loans and other debt, living longer with parents, and not having children until later, if at all. The conditions of wealth and labour may be further exacerbated when young adults fall ill, having a meager cushion of savings to support their time off work. Perhaps more importantly, those without jobs do not have employer-provided healthcare coverage and with a pre-existing condition like cancer may either be denied coverage or charged a high premium for it. Kairol Rosenthal (2009) notes that their financial lives are among the most at stake during and after treatment: “for many of us, cancer is not necessarily an open door on the future, but rather an extremely large financial question mark upon which our big dreams hinge” (p. 24). These stories of lower wealth may question the extent to which financial independence—one major aspect of self-authorship—is both attainable and relevant to young adulthood within current economic conditions.

Another important material condition is the advancement of technology, especially media technology, and its permeation into everyday young adult life. According to research conducted by psychologists Rosen, Carrier, and Cheever (2010), the young adult demographic is to a large degree defined by its spike in media consumption and synaptic ties to the internet, hence the researchers’ references to the cohort as the “iGeneration” or “Net Generation.” They based their claims on surveys indicating that from morning to evening today’s youths are engaged with either computers, televisions, cell phones, media players, or video games (Rosen et al., 2010).

Online interactions alone may have a crucial part to play in how young adults experience cancer, or any illness. ‘Google’ may be consulted before a physician is, prior to diagnosis as well

as during and after treatments. From their homes young adults have unprecedented access to medical information—reliable and not—and may research both conventional and non-conventional treatments to inform their medical decisions. Furthermore, support groups, advocacy organizations, and online forums rely upon a strong internet presence for connecting young adult cancer patients with one another, including those in rural, remote, or small-scale communities who may never meet another younger patient locally. This unprecedented access to digital media may thus affect how young adults interpret themselves and tell their stories.

3. Young Adult Meanings and Ways of Being

The social and material conditions of their upbringing have likely shaped today's young adults in complex ways, revealing historical changes in how young adulthood is understood and lived. Media technology, for instance, has played a crucial part in young adults' exposure to what has been called a "globalized world" (Savage et al., 2006, p. 143); for example, the internet and television enable as never before cross-national interactions and cross-fertilization of cultural discourses across the world. Today's young adults are exposed to both the diversity of voices within media outlets as well as the local social worlds of meanings and practices within which they live, and in response have created "bicultural" (or, perhaps, 'polycultural') identities within their multiple worlds and networks of interaction (Arnett, 2002). Thus, the processes of globalization may have multiplied the meanings and ways of being available to young adults.

A deep ambivalence is said to reside in many young adults' sense of self: they are seen as uncertain about their religious beliefs, dashed with bits of suspicion, indifference, and biases passed on from secular media portrayals of religion (Savage et al., 2006, p. 21); they may be caught between socialized expectations of limitless opportunities and unanticipated disruptive experiences, whether of illness, unemployment, poverty, social isolation, or rejection (Young-

Eisendrath, 2009, p. 21); and they may be lost in explorations of their identities for longer periods of time than earlier generations (Arnett, 2011; Henig, 2010; Savage et al., 2006, p. 153).

It is sometimes said we are in an “age of anxiety and depression” (Twenge, 2006) striving for a better “age of self-confidence” (Young-Eisendrath, 2009). Psychologist Sara Savage and colleagues (2006) tried to put these tensions into an existential framework through what they saw as the most common stories young adults tell about themselves. Young adults’ so-called “happy midi-narratives” expressed ambivalence yet optimism about the future, and conceived of a local, small-scale (i.e., “midi”) world centred around an individualized self and reflective of postmodern aversions to larger, “meta” narratives (p. 37-39). I perceive these observations as signs of dominant discourses that are entering into and being perpetuated by young adults’ narratives; that is, instead of revealing the *zeitgeist* of the current generation, these studies mark recent shifts in how young adulthood is formulated through dialogue between dominant discourses (e.g., of self-esteem, choice, and positive thinking) and individual narratives.

Correlatively, there are significant changes in young adults’ praxes, possibly related to current conditions of young adult life in North America. Developmental psychologist James Marcia (1973), for instance, observed that adolescence and young adulthood are often times of “moratoria,” liminal times of exploring different ways of being before settling on a matured identity marking a particular path for the rest of life. Among many notable hiatuses taken during this time are ‘delays’ or departures from what is called the “traditional cycle,” or “traditional milestones,” of adulthood in modernity: graduate from post-secondary education, leave home to purchase one’s own, develop a stable career, acquire a spouse, and produce a family (Carrick, 2013; Henig, 2010; Henig and Henig, 2012; Savage et al., 2006, p. 4). This ‘traditional’ course reflects the ideology of young adulthood in its emphasis on integration and independence.

Although these horizons of expectation still hold sway and can be seen in their “mid-narratives,” many young adults are in all sorts of ways breaking with tradition—or, “not growing up,” according to critics of this social change (see e.g., Henig, 2010). Recent statistics in North America show that around one half of women and one third of men had gone through the traditional cycle by the time they were thirty, compared to 1960 when the rate was closer to two-thirds for both genders (Henig, 2010). Forty percent of young adults move back home in their twenties—usually for financial reasons—hence the attribution “boomerang kids” (Carrick, 2013; Henig, 2010). With the popularity of premarital sex and birth control, both teen moms and voluntarily childless couples are more common now (Henig, 2010). Careers are not leaving the ground quite as early and may switch directions more than once before even taking off (Coates, 2012). These and other emerging trends suggest an ambiguous trajectory or perhaps, according to sociologist Frank Furstenberg (2010), even a “new timetable for growing up” (p. 80).

Some of the noted historical changes may be partly due to the social and material conditions of young adulthood today. Moratoria may be, on the one hand, uninvited liminality brought on by economically hard times and multiplying discourses about life’s options and choices; yet, on the other hand, there may be culturally supported liminalities, spaces of experience and horizons of expectation socially constructed as temporary escapes and adventures from responsibilities³. Parental permission to stay at home into one’s thirties, governmental loans and support for undergraduate and graduate education, growing acceptability of spouses who wait to have children, and many other practices point to this possibility. What we may be seeing, at least in their current incarnations, is a mix of chosen and involuntary suspensions of meaning and being among today’s young adults.

³ While I am restricting my focus to North American young adults, these moratoria are widely sanctioned in other upper- and middle-income countries, and even among wealthier classes in low-income countries throughout the globe (Arnett, 2011).

Though not exhaustive, this review outlines some of the life circumstances that young adults may carry with them into lived experiences of illness. We see that in many aspects of home and work lives young adults may be ‘in-between’ different narrative environments. They are in dialogue with a multiplicity of discourses, local and global, which may influence their own worldviews and practices. Savage and colleagues (2006) referred to young adults of the present as a “hinge generation,” raised within specific community traditions aspiring to a particular social order as well as participating in emerging and diverse global traditions through informational and social media (p. 150). While I am critical of referring to young adults as a cohesive ‘generation,’ this is a helpful metaphor for imagining young adults as pins wedged within local social frames of meaning and being, yet linked to gateways into new narrative environments and spaces of experience. Deviations from ‘traditional’ markers not only signify fluctuating master narratives but also shifting lived practices of young adulthood.

4. Emerging Adults?

Within psychology, the term “emerging adulthood” is being used more frequently to denote people in their late teens and twenties who are ‘in-between’ adolescence and young adulthood (Arnett, 2000)—an interim period marked by prolonged periods of familial dependence, self-searching, and bachelorhood. Psychologist Jeffrey Arnett (2011), who coined the term, defined emerging adulthood as “*the*” age of possibilities, of identity explorations, of unstable home and work lives, and of absent responsibilities and social control.

‘Emerging adulthood’ may be an apt concept for talking about young adult cancer patients, who often have to move back home, rely on parental care and finances, and reevaluate their assumptions of self and life (D’Agostino, Penney, and Zebrack, 2011). However, there are reasons to object to this concept as well. First, Arnett studies a much more narrow age group (18-

29) than I studied in my research (18-45)⁴, based on his ideas about the duration of this liminal stage. More fundamentally, the people I interviewed had varied significantly according to whether they even satisfied Arnett's criteria for emerging adults—including those within the defined age range. Conceptions of 'emerging adulthood' have been criticized as an image of White, privileged young adults who do not suffer many of the limitations to their possibilities imposed by illness, disability, sexism, racism, or poverty (see e.g., Henig, 2010). Arnett (2011) himself admitted to the limited applicability of his theory.

A related concern is with the relation of 'emerging adulthood' to cultural discourses. Arnett (2011) claimed that this life stage marks a "nadir of social and institutional control" (p. 266), which is a very peculiar statement within a chapter about the sanctioning of moratoria across different cultural contexts. Local social permission and endorsement of emerging adulthood *is* a form of social influence, and is subject to ideological use as with the case of adolescence. Nevertheless, if Arnett understands the term as such then it may be inappropriate for me to use it. In addition, 'emerging adulthood' has not been commonly put to use in dominant oncological discourses. 'Young adulthood' continues to be the preferred term; many patients, doctors, and families participating in these discourses refer to young adulthood as a distinct biomedically and psychosocially relevant category. Thus, it seems fitting to operate within the discursive concept more familiar to the social actors involved.

5. Conclusion: Approximations of Young Adulthood

I am cautious about using the above terminologies, notwithstanding possibly shared narrative and lived experiences among young adults. 'Emerging adulthood' seems to be a useful term but one rarely used in oncological settings or in reference or discursive constructions of self. 'Generation Y' places today's young adults into social context, but does not seem to balance

⁴ I make the case for my chosen age range in the following section.

its macro focus with attention to local social worlds of meaning and being. Despite their limitations, these terms inform us of some current spaces of experiences and horizons of expectation: both sanctioned and unwanted moratoria, the impact of globalizing technologies, and deviations from traditional milestones. Consideration of these historical realities brings to light the contexts and limits of the ideology of young adulthood, which seems to overlook them.

‘Young adulthood’ is itself a problematic term, lumping together people from many different walks of life into a collective; however, it is useful to the extent of establishing *approximations* of some social and material conditions that today’s younger populations encounter. Among the different ways I could refer to the population of interest to me, I chose ‘young adulthood’ as a familiar yet relatively loose term to be employed without as high a risk of constructing homogenous subjects. The above review is the basis for my evaluation of young adult oncology (especially psychosocial discourses) in the following section.

Oncological Discourses of Young Adulthood

Introduction and National Contexts

Among other contexts such as gender (e.g., Seale, 2002; Sormanti, 2010) and socioeconomic status (e.g., Williams, 2004), age is gaining increasing attention within oncological research and clinical settings. For instance, in their work with aging cancer patients, Blank and Bellizzi (2008) called for a “marriage of the gerontologic and oncologic perspectives” (p. 2574) in order to properly understand and care for the distinct difficulties cancer patients face as they grow older. A similar call has recently been issued for young adults with cancer in pockets of North American oncological discourses (e.g., D’Agostino et al., 2011; Pritchard, Cuvulier, Harlos, and Barr, 2011; Zebrack, 2011).

Many of the discourses advocating for young adult cancer care say that, compared to other age groups, young adults are relatively invisible, ignored, and overlooked within oncological institutions and research (Barr, Rogers, and Schacter, 2011; CCS, 2009; CPAC, 2010; Sutcliffe, 2011). Many cancer centres (or wards) in Canada and abroad have specialists trained in more established sub-fields of pediatric or geriatric medicine, while very few have training specifically for adolescent and young adult (“AYA”) oncology (Barr et al., 2011; Nathan, Hayes-Lattin, Sisler, and Hudson, 2011; Ramphal, Meyer, Schacter, Rogers, and Pinkerton, 2011). For example, while there are sixteen pediatric oncology and hematology centres across Canada, there are only two young adult cancer centres (CIHR, 2009)⁵.

Pediatric oncologist Ronald Barr (2011a) has written, “The needs of AYA with cancer are poorly met by the conventional dichotomy of the pediatric and adult health care systems” (p. 2239). Young adults who do not have access to the few facilities or experts may go to either an adult or a pediatric cancer centre for treatment depending on their age, type of cancer, and geographical location (Nathan et al., 2011). Treatment outcomes for young adults are believed to suffer as a result of too few specialists and specialized centres in Canada (Tonorezos and Oeffinger, 2011). This relative absence carries on south of the border as well; Kairol Rosenthal (2009) observed that “out of 13,000 practicing oncologists in the United States, a scant handful focus exclusively on young adult oncology. The majority of our doctors have zero expertise with the physiology of young adult cancer patients” (p. 139).

Furthermore, young adult cancer is seen as poorly represented in oncological research. Pediatric, adolescent, and young adult cancer research (across biomedical and psychosocial disciplines) shares a mere \$4 million provided each year by the Canadian Institute of Health

⁵ They are the Adolescent and Young Adult Oncology Program housed within Montreal’s Segal Cancer Centre, Jewish General Hospital, and Toronto’s PYNK Breast Cancer Program for Young Women at the Odette Cancer Centre, Sunnybrook Health Sciences Centre.

Research, making up approximately 50% of the funding provided for young adult cancer research in Canada (CIHR, 2009). Some governmental, community, and research bodies have called for better categorization, research, advocacy and surveillance of young adult cancers, like CIHR (2009) and the Canadian Cancer Society (CCS, 2009). Two organizations committed to improving AYA outcomes—the Canadian Partnership Against Cancer and C17—tried to bring more light to the issue by creating a national task force for pediatric, adolescent, and young adult patients, composed of researchers, patients, policy makers, and health practitioners. Much of the published research on AYA cancer came out of the meetings recently held by the task force (e.g., Barr et al., 2011, 2011b; Nathan et al., 2011; Zebrack, 2011).

National attention to young adult (and adolescent) cancer has caught on quicker in some countries than others. The British advocacy group Teenage Cancer Trust began in the early 1990s pushing for improved medical care; in the United States LiveStrong (Lance Armstrong’s foundation) created a Young Adult Alliance in 2006. Widespread concern regarding young adult cancer has only quite recently become part of the national landscape of major oncological discourses in Canada (and, even now, it is still somewhat on the fringes)⁶. This may be due to the fact that young adult cancers (using a 20-44 age range) make up only 6% (men) and 11% (women) of cancers diagnosed in people ages 20 and over (CCS, 2006).

Due to select leading governmental and non-governmental organizations, conversations and ‘awareness’ are growing relatively quickly in the public sphere. The first organization in the country to engage in distinguishing and advocating for young adults was Young Adult Cancer Canada (formerly RealTime Cancer), a not-for-profit group founded in 2000 by cancer survivor Geoff Eaton. A few years later, health researchers as well as larger health organizations began to

⁶ Almost nothing had been published on AYA oncology until the 21st century, with some exceptions specific to adolescent cancer (e.g., see Ettinger and Heiney, 1993; Kellerman and Katz, 1977; List et al., 1991; Struber and Kazak, 1999) and young adult cancer (e.g., see Roberts et al., 1997; Rowland, 1990).

publish reports and release news on young adult cancer, including community organizations such as the Canadian Cancer Society (2006, 2009, 2012) and the Canadian Partnership Against Cancer (2010, 2011), and governmental organizations such as the Canadian Institutes of Health Research (2009). The awareness produced by these discourses has enabled the development of research programs, support services, and targeted clinical trials for many young adults with cancer.

The benefits or ‘productivity’ of emerging discourses on young adult cancer cannot be understated, yet they are not without their limitations. In the process of constituting ‘young adults’ as a cohesive group, oncological discourses have constructed subjects of questionable characteristics and desires. In particular, biomedical statistics and developmentalist narratives have been used to differentiate young adults from other patients in some dubious ways. To be fair, all discourses have a potential element of partiality and failure to them—they have both enabling and disabling effects—but because in a given cultural context few discourses dominate and many remain marginal, the resulting spaces of experience and horizons of expectation are always constrained (Ricoeur, 1985, p. 208-209).

The point of my critique is to not to strip credence from discourses about shared cancer experiences, but to enable multiple voices to have their say in what meanings and ways of being are available to young adult cancer patients. I aim to problematize—not refute—dominant discursive constructions of young adults with cancer, with the purpose of distancing them from ‘natural attitudes.’ Participating in alternative or marginal discourses, I try to disrupt some taken-for-granted assumptions about the lived experiences and primary stakes of young adults living with chronic illness. In addition, I have two constructive goals in mind in my critique of dominant illness discourses. The first is to show how young adult cancer is commonly

constructed or performed, which is a crucial background to how the young adults in this study interpreted themselves. Second, I hope to reveal and reopen life paths that dominant discourses may be censoring, discouraging, or covering up. Within this critical space I propose a narrative approach to studying young adult cancer.

I concern myself primarily with the *research literature* within oncology—despite the possibility that the majority of healthcare practitioners might not follow this research. My concern stems from the potential impact that dominant representations may have on care policy and practice. Some distresses borne by patients and their families may be created or exacerbated by healthcare practices that follow from unquestioned assumptions.

With that point in mind, my evaluation does not place responsibility solely upon healthcare researchers and practitioners. Discourses around young adulthood are neither formed just by researchers and clinicians nor do they serve as purely academic or professional matters; they also grow out of the voices of patients, their families, and other stakeholders who tell their stories in online videos, advocacy pamphlets, published texts, and interactions with their caregivers, researchers, etc. My critique is of certain *dominant representations* within young adult oncology regardless of who is perpetuating them, in recognition that patient narratives—as participants in discourses—may contribute to ideological or politicized claims about suffering and meaning (see e.g., Smith, 1993).

I appreciate that many benevolent intentions lie behind these discourses, such as raising awareness of young adult cancers, isolating the distinct concerns of young adults, and convincing others that young adults need better care. In order to achieve these goals, many articles pitch to their audiences of practitioners and policymakers that there exist widespread ‘problems’ with young adults and broadly applicable ‘solutions.’ Yet, some of the proposed reforms risk doing

violence to the very people they are meant to serve, much in the same way that cohesive self-stories may do violence to chaotic or disjointed experiences (e.g., Heidt, 1991; Rimmon-Kenan, 2002). In their efforts to constitute the group ‘young adult cancer patients,’ they may conceal, marginalize, or foreclose the multiple meanings and ways of being that make up the complex lives of today’s young adults.

Within my review I discuss two sets of dominant discourses: a) biomedical discourses regarding the biomedical distinctiveness of young adult cancer; b) psychosocial discourses concerned with age-specific developmental issues. For my purposes here, I critically study the rhetorical side of these discourses, the strategic/selective uses of research knowledge toward particular (though often implicit) practical ends, and the limitations they impose on understanding young adult cancer. I conclude from these evaluations that a critical narrative program of research may provide complementary and informative images of young adulthood.

A) Dominant Biomedical Discourses

I begin my evaluation with biomedical discourses of young adult cancer. Below I discuss four common ways in which young adult cancers are constructed as distinct from the cancers of younger and older people: first, by way of age-specific definitions of young adulthood; second, through identifying biomedical distinctions; third, by employing enflamed incidence and mortality rates; and fourth, with proposals for more biomedical research to justify their rhetoric. As I engage each discourse I critically evaluate the logic and intentions behind such representations.

1. Age-specific Definitions of Young Adulthood

The majority of attempts at defining young adulthood use chronological age as an appropriate signifier of young adult status (instead of, for example, psychosocial markers,

patients' self-definitions, cultural rites of passage, etc.). With that signifier a vast array of definitions scatters across different research publications, including those by the same authors. Cancer Care Ontario (2006), the first Canadian-funded, non-for-profit organization to issue a publication specifically on young adult cancer, defined young adulthood as 20-44 years old. They cited a gendered rationale for this choice: "It stretches from 'adolescence' (generally defined as ages 15–19) to the time of life around which, in women, menopause induces quite marked changes in the cancer profile" (p. 6). No other publication has since reiterated those same parameters, suggesting it has fallen out of vogue. Among a small sample, the numbers have varied from 15-39 (Odo and Potter, 2009), 18-35 (Snobohm, Friedrichsen, and Heiwe, 2010), 21-45 (Clausen, 2010), 22-35 (Roberts, Severinsen, Carraway, Clark, Freeman, and Daniel, 1997), to 31-47 (Dunn and Steginga, 2000).

There are a number of complications to setting out a hard and fast age range. First of all, the relevance of age varies depending on the type of cancer; for instance, lymphomas are most common in 15-19 year olds, while breast and colorectal carcinomas are more common among people 20-29 years of age (Bleyer, Barr, Hayes-Lattin, Thomas, Ellis, and Anderson, 2008). The characteristics of young adulthood are further obscured by the fact that the category is frequently expanded to include adolescence, breeding the acronym "AYA" now used in reference to patients who are deemed to be neither full-fledged adults nor children. The CCS (2009, 2012), for example, used a range of 15-29 years old when they incorporated adolescents into their categorization.

The Canadian Partnership Against Cancer (2011) adopted this updated AYA definition, but other researchers⁷ who write of AYA cancer provide conflicting ranges of 11-22 (Decker, Hasse, and Bell, 2007), 13-21 (Kameny and Bearison, 2002), 14-25 (Grinyer, 2009), 15-25

⁷ This list includes research from both Canada and the United States.

(Grinyer, 2007), 15-39 (Bleyer et al., 2008), 16-22 (Kyngas et al., 2000), 16-30 (Crawshaw, Glaser, Hale, and Sloper, 2009), 18-25 (Grinyer and Thomas, 2004), and 18-40 (Zebrack, 2008). A 2011 special supplement to an issue of the journal *Cancer*—run by the American Cancer Society—published a series of articles from participants of an AYA cancer workshop in Toronto, and even among them were incongruent definitions stretching from 15-25, 15-29, to 18-35 years of age (e.g., D’Agostino et al., 2011; Pritchard et al., 2011; Zebrack, 2011).

The purpose of laying out this range of age ranges is to show that defining young adulthood is an imprecise, inconsistent, and controversial venture. On the one hand, many of these parameters seem arbitrarily restrictive, with no obvious reasoning behind them. On the other hand, one may be remiss to take a more inclusive approach; adopting the lowest and highest ages suggested, one would lump 11-year-old elementary students together with 47-year-old workers, possibly with grandchildren, into the same ‘group.’

Nevertheless, we must start from somewhere. Setting out a framework at least allows us to make comparisons and contrasts. It may just be that in the process we discover the flaws in our own design, but in order to get there we need to take a bit of a leap. The leap taken for my study was for a wide range between 18-45 years of age—not an impeccable choice by any stretch, but a relatively inclusive range enabling people across three decades to demonstrate their commonalities and differences. This decision was influenced by some of the institutional discourses my supervisor and I were involved with when we sought research funding. When Dr. Teucher developed a grant proposal for the Social Sciences and Humanities Research Council in 2008, the differentiation of *adult* cancer patients into three age groups of 18-45 ("young adults"), 45-65 ("middle age"), and 65 and above ("aging") was not uncommon and seemed as useful as well as problematic as any other. At that time, generally only quantitative research had been

done with young cancer patients but hardly any qualitative research and Dr. Teucher was successful in receiving tri-council funding for this project. My supervisor and I continue to have our suspicions and hesitations in adopting this age-related framework of 18-45 and I have laboured above to show that no age range, including our own, is without its limitations.

The Canadian Institutes of Health Research—another influential Canadian governmental organization participating in these discourses—summarily articulated the challenges of setting down a firm definition. In a 2009 conference report on the aforesaid AYA workshop, which was funded by CIHR, they expressed reluctance in playing this guessing game:

Although it is generally accepted that the pediatric age range is 0 to 14, and that adolescents range from 15 to 19 years of age, the definition of a ‘young adult’ has less clarity, particularly at the upper limit - ranging from 29 to 39. It is recognized that not only do individuals have very different clinical, developmental and psychosocial needs that are often age-related but that the incidence and biology of the tumours and the expected clinical outcomes also differ significantly with age at diagnosis. Meeting participants felt that it would therefore be appropriate, rather than set a fixed upper limit in the young adult age range, to base the definition on the incidence and specific biology of the tumour under study and the needs of the patient both at the time of diagnosis and going forward after treatment (p. 8).

In the absence of a “fixed” age-related signifier of young adulthood, the task force proposed biological markers and incidence rates to distinguish young adult tumours from those of other age groups. It is to these two other signifiers and their limitations we shall now turn.

2. Biological Markers

In terms of arguments from physiology, young adults are often portrayed, sometimes with adolescents (abbreviated as AYAs), as having a distinct set of common cancers during this time of life (Bleyer et al., 2008; CCS, 2009; CPAC, 2011; McGoldrick, Gordon, Whiteson, Adams, Rogers, and Sutcliffe, 2011; Tonorezos and Oeffinger, 2011). 90% of all cases of cancer in

adolescence and young adulthood are represented by just ten of the 200+ forms of cancer⁸; some cancers occur at their highest rates in young adulthood, including Hodgkin's lymphoma, testicular cancer, Kaposi sarcoma, and others (Bleyer et al., 2008). It is also argued that there are possible differences in the genetics, epigenetics, physiology, and pharmacology of the same type of cancer between 'AYA' patients and people in different age groups; for instance, hormonal differences as a result of age and genetics are suspected to create cancer with distinct behaviours, including rates of acceleration, symptoms or expressions, and responses to treatment (Bleyer et al., 2008; CCS, 2009; CIHR, 2009; CPAC, 2010).

Young adults have been described as a "crossover" age group according to the types of cancers that are common to them (CCS, 2006). About 85-90% of cancer in later adulthood are *epithelial*⁹ cancers, that is, carcinomas of the skin tissues or tissues lining organs and cavities (Bleyer et al., 2008; CCS, 2006)¹⁰. On the other end, about 90% of cancers in youth (from birth to adolescence) are classified in pediatric oncology as *non-epithelial* cancers, that is, sarcomas of the connective tissues (i.e., bone, muscle, cartilage), gliomas of the neural tissues, lymphomas of the lymph tissues, or leukemias of the blood tissues (Bleyer et al., 2008; CCS, 2006). In contrast to both age groups, 37% of young adult cancers are epithelial while 47% are non-epithelial, signifying a transitional phase during which certain bodily tissues become more vulnerable to cancer while others less so (CCS, 2006).

This "crossover" image of young adult cancer can be misleading. Non-epithelial cancers are said to make up 64% of male young adult cancers while comprising only 25% of female young adult cancers, and while in all other age groups men have higher rates of cancer, the

⁸ These are breast cancers, lymphomas, melanomas, ovarian and cervical cancers, thyroid carcinomas, sarcomas, testicular cancers, colorectal carcinomas, leukaemias and brain tumours (Bleyer et al., 2008).

⁹ Epithelium is the form of tissue that lines cavities, makes up glands, and coats the surface of many bodily structures.

¹⁰ Carcinomas are the most common type of cancerous growth (Alschuler and Gazella, 2010, p. 4).

reverse is true in young adulthood (CCS, 2006). Beyond that, age-specific incidence rates accelerate much more for women across young adulthood, so that in their 40s women have nearly double the rate to men: 118 vs. 224 cases per 100,000 (CCS, 2006). Thus, there are gender and age differences that complicate the above perceptions of young adult cancer, with a disproportionate number of women relating more to the carcinomas of older cancer patients and, in turn, altering the scales to appear more balanced between epithelial and non-epithelial malignancies.

Even though a number of relevant distinctions seem to vary by type of cancer, age *within* young adulthood, gender and individual patient biology, common conclusions are that “AYA oncology would benefit from the creation of its own classification system” (Bleyer et al., 2008, p. 297). Accounting for differences that go well beyond physiology, we have a less cohesive image of young adult cancers, one that is ‘decentered,’ scattered by qualifier after qualifier, weakening the case for a “distinctive biology” (Bleyer et al., 2008). This criticism moves us away from an essentialized image of young adult cancers. We find similar difficulties when we look to incidence and mortality rates.

3. Incidence and Mortality Rates

Other statistical measures have been used to spot young adults from the crowd, perhaps the most notable being disconcerting incidence rates and outcomes. Most forms of young adult cancer are claimed to have risen in incidence over the last couple of decades (CCS, 2006, 2012; CPAC, 2010). Young adults have allegedly also seen less improvement in the five-year survival ratio than children and older adults, and death rates are seen as particularly high for some non-epithelial cancers such as leukemias, gliomas, and non-Hodgkin’s lymphomas (Barr, 2011; Bleyer et al., 2008; CPAC, 2010; McGoldrick et al., 2011). Looking more broadly, cancer is the

second leading cause of death for young adult women and the third leading cause for young adult men (ages 15-35), alongside accidents and suicide (Statistics Canada, 2009).

Discourses around the ‘crisis’ of young adult cancer are sometimes balanced by more hopeful discourses about the effectiveness of modern medicine in improving outcomes. Often, a selective presentation of statistics is involved in order to shift the discourses one way or another. Extending the upper limit of young adulthood from 29 to 39 years of age, for example, actually doubles the incidence rate for the AYA group (Barr, 2011). On the other hand, if one excludes female epithelial cancers from the analysis, overall young adult cancer rates seem to have actually *decreased* (CCS, 2009)—just as the “crossover” principle is not so obvious when accounting for gender and age differences in typology. In addition, despite slower advances than other age groups, young adult mortality has also *decreased* over the last couple decades (CIHR, 2009; CCS, 2006), improving the five-year survival ratio from 80 to 85% (Barr, 2011; CPAC, 2010; Nathan et al., 2011). Of course, broken down further the image is more complex; though young adults die more often from some kinds of cancer over others, in the case of melanoma they die *less* often than younger or older patients (Bleyer et al., 2008).

We see here that incidence and outcome statistics can be and have been used to either: a) enhance the perceived plight of young adults, thereby rallying support for funding, research, and interventions; or b) enhance the perceived advances of medical interventions, thereby protecting or even inflating the image of biomedicine as a “cure-promising authority” (Rimmon-Kenan, 2002, p. 22). Often statistics are used in oncology—incidence and mortality rates as well as survival ratios—to construct a palpable image of cancer, functioning as a “technology of presencing” according to medical anthropologist Sarah Lochlann Jain (2007, p. 78). As an ideological construct, they are deceptively certain in their representations and yet “bloodlessly

vague” about the present and future (Jain, p. 78): Are the circumstances for young adults getting better or worse? Are current medical practices failing them or saving them? This ambiguity affords the use (or abuse) of statistics toward contradictory arguments. We may conclude from this that using medical statistics to justify the reification of ‘young adult cancer’ is, at the very least, an equivocal attempt to illuminate the extent and severity of the disease in this age group.

4. Biomedical Proposals

Despite their assurances of young adult distinctiveness, oncological discourses around young adult cancer sometimes admit that little is known about their cancers in terms of genetic and environmental origins, long-term effects of treatment, and possible trends in incidence (CCS, 2006). Two major areas are seen as needing more research: a heavily biomedical agenda of improving survival and a predominantly psychosocial agenda of enhancing quality of life (Barr et al., 2011; CIHR, 2009). Some may see these two lines of inquiry as complementary, and together holding potential for an integrative approach to illness; however, they are treated hierarchically with biomedical research on cancer treatments receiving priority over psychosocial studies on cancer support (Barr, 2011; CIHR, 2009)¹¹. Tonorezos and Oeffinger (2011) wrote that, “of primary importance in AYA cancer survivor research is the ongoing effort to improve cancer outcomes in this age group” (p. 2298). The chosen commitments are defended by appeal to the incidence and mortality rates of young adults—statistics, I have already noted, that are strategically modified and crafted to this purpose.

As laudable as these directives are (and I will not deny their importance), there is an underlying problem with the proposed course of action. With so many young adults and people of other age groups surviving cancer (from 45% to 90% rates for the most common cancers),

¹¹ While nobody is necessarily stopping psychosocial research from happening, because the single most contributing organization to financing this area of research, CIHR, has indicated its preference for biomedical research, there are few financial opportunities and incentives to pursue it.

long-term issues of survivorship seem to be more and more prevalent. Among those issues are emotional, social, existential, and economic challenges (McGoldrick et al., 2011; Tonorezos and Oeffinger, 2011; Zebrack, 2011). Perhaps, then, the stakes should not be monopolized by one particular research agenda, which defines in a limited way what concerns young adults most.

The primary objectives of AYA research seem to be directed toward a medical “telos of cure” (Frank, 1995, p. 83), which concerns itself narrowly with removing disease. With this lens, it is easy to engage in what I referred to in the last chapter as medical Cartesianism, a problematic bifurcation of person and disease, restricting focus to medically objectified young adult bodies and bracketing out their subjectively lived bodies within local social worlds. In sum, care for the multifaceted life challenges faced by young adults may be forsaken in efforts to treat their physiological problems.

Survival is no doubt of great significance to the majority of young adults, but is it the only, or even primary, issue at stake? Social researchers Kleinman and Kleinman (1991) argued that, “While preservation of life, aspiration, prestige, and the like may be shared structures of relevance for human conditions across societies, that which is at stake in daily situations differs (often dramatically) owing to cultural elaboration, personal idiosyncrasy, historical particularities, and the specifics of the situation. What is at stake in life settings, then, is usually contested and indeterminate” (p. 277). Given the limited research and understanding of young adult cancer, it seems we need better understanding of the stakes in young adult cancer before committing selectively to one particular agenda.

5. Conclusion: Creating a Critical Distance from Biomedical Rhetoric

Within this first part on dominant oncological discourses, young adults are constructed in terms of their age, tumour biology, incidence rates and mortality/survival statistics. None of

these constructions are without their limitations; the age cutoff of young adulthood is so notably arbitrary that some have dispensed with an umbrella definition of young adulthood, yet statistical analyses are still selectively chosen (not randomly, but not objectively either) to make a case for distinct young adult biology, incidence, and mortality. Proposals for research and clinical supports seemed to be based on this understanding, filtering focus into self-serving biomedical interests and perpetuating medical Cartesianism.

To some extent, this mystification is necessary to facilitate concern for and investment in improving the well-being of young adults with cancer. I mean not to deny that cancer is an important health issue for young adults, or that all of the above studies in the field of AYA oncology are nothing more than a hall of mirrors. I mentioned in the previous chapter that language is not empty, but an exercise that both reveals and conceals at the same time. My intention here is to reveal that which is often concealed—the questionable logic and alteration of numbers—creating a critical distance from the frequently employed rhetoric used to convince audiences of the distinctness of young adult cancer. In turn, I raised questions about other possible stakes and contexts that may be at play while living with cancer. This mode of doubt afforded some distance from the dominant rhetoric while I was investigating young adult cancer. I pursue a similar goal below with regard to discourses around the psychology of illness.

A) Dominant Psychosocial Discourses

In the following review, I discuss two recurring discourses in the psychosocial literature on young adult cancer: purportedly underserved psychosocial and developmental issues and individual responsibility for prevention and treatment. These discourses tie more strongly into the scopes of my dissertation—exploring the biographical and existential challenges of cancer and evaluating the ideology of young adulthood—than do the aforementioned biomedical

discourses. My engagement with them here sets the stage for their reemergence within my analyses of young adults' narratives.

1. Psychosocial and Developmental Issues

Other sets of discourses are growing in AYA oncology, not from the interpretive frames of biology or epidemiology, but from psychosocial and developmental perspectives. They are predicated upon neo-Eriksonian assumptions that young adulthood is a distinct period of the life course, peppered with developmental concerns not encountered until such time (CCS, 2006, 2009; CIHR, 2009; CPAC, 2011; McGoldrick et al., 2011; Pritchard et al., 2011; Tonorezos and Oeffinger, 2011; Zebrack, 2011). Engaging in *developmentalist* discourses, many social scientists argue that the psychosocial issues of young adult cancer patients¹² are distinct from those of other age cohorts, especially with regard to the prevention or delay of age-specific 'developmental tasks' (Decker et al., 2007; Grinyer, 2007; Grinyer 2009; Kellerman and Katz, 1977; Roberts et al., 1997; Rowland, 1990; Woodgate, 2005; Zebrack, 2011).

Some of the suggested dominant 'tasks' of young adulthood include independence from one's parents (i.e., emotional, physical, financial, etc.), a secured body-image and sexuality, a stable and intimate relationship (leading to marriage or long-term commitment), social integration among peers, and a future orientation on family life and career development (CCS, 2006, 2009; CIHR, 2009; CPAC, 2011; D'Agostino et al., 2011; Ettinger and Heiney, 1993; Gavaghan and Roach, 1987; List, Ritter-Sterr, and Lanksy, 1991; McGoldrick et al., 2011; Odo and Potter, 2009; Struber and Kazak, 1999; Woodgate, 2005; Zebrack, 2011).

From these studies an echo can be heard of psychologist Erik Erikson (1980), who said of young adulthood: "when childhood and youth come to an end, life, so the saying goes, begins: by

¹² Some of the articles subsume both young adults and adolescents—typically from ages 15 to 39—under a unique age cohort, but my commentary does not make the same extension into mid-teens, who cannot legally marry or access other privileges of adulthood.

which we mean work or study for a specified career, sociability with the other sex, and in time, marriage and a family of one's own” (p. 96-97). We see here the enduring legacy of the ‘traditional cycle’ narrative of adulthood, first discussed much earlier in this chapter.

The above tasks seem to parallel the imperatives found in many narrative studies of identity development (i.e., narrative coherence and self-authorship), not surprising given the residual voice of Erikson in both sub-fields. The ‘task’ of independence seems quite correlative to the imperative of self-authorship, commanding young adults to ‘take charge’ of their lives. Images of stable home and work selves (i.e., marriage, career, social integration) seem to articulate a coherent and predictable narrative of ‘successful’ young adulthood. Together these tasks could be seen to make up the biographical and existential concerns to young adult life, defining the contours of a person’s forms of meaning and being during this time of life: drawing a bridge between self and body through sexual practices and physical appearance; defining one’s perspective of time by a strict focus on future plans and relative disregard for their pasts; organizing social relations through ‘fitting in,’ getting married, and procreating; and so on. In sum, dominant discourses of AYA oncology and narrative identity development seem to assert that the integration of life experiences and the attainment of self-determination are the normative paths toward transcending illness and developing into adults.

It is often believed that diagnosis of a chronic illness will disrupt a young person’s progress toward these tasks, leading to biographical and existential crises. Recall some of the many ways that illness represents alienation or “unhomelike” being-in-the-world (Svendsen, 2000)—altered embodiment and consciousness, awareness of mortality and time, disrupted activities, social isolation—and we can see how these alleged tasks may be endangered. For example, nursing researcher Roberta Woodgate (2005) argued that bodily alienation can produce

an array of “different ways of being in the world” among adolescents, perceiving their bodies as “rebellious, unreliable, sensitive, dependent, conspicuous, vital, and ‘in therapy’” (p. 13). A younger patient’s newly acquired body-image, sexuality, and independence may be radically destabilized by chronic pain, limited energy, and other psycho-physical effects of cancer (e.g., Grinyer, 2007; Snobhohm, 2010; Woodgate, 2005). In addition, focus on future family and career plans may be thwarted by the prospect of dying young, reduced attention or motivation from fatigue, or fears of being rejected by potential partners or employers (e.g., Grinyer, 2007; Odo and Potter, 2009).

When these tasks are jeopardized, young adults are often expected to experience heightened levels of distress (Decker et al., 2007; Grinyer, 2007; Kellerman and Katz, 1977; Roberts et al., 1997). Some have even argued—dubiously I might add—that young adult cancer is possibly more distressing than for cancer patients of other ages: “It is manifestly not pleasant to develop cancer at any age, even in extreme old age, but in the most active and productive years of life, with maximum family and social responsibilities, it is a particular tragedy” (CCS, 2006, p. 6)¹³. This perceived distress may carry on for years due to the initial shock of the diagnosis and liminal phases of treatment and recovery.

As a case in point, social worker Carol Decker and colleagues (2007) found that young adult patients often continue to feel uncertain about the present and the future for years after diagnosis. Newly diagnosed patients expressed heightened worry regarding anticipated pain, their illness’ trajectory, potential loss of independence, and the roles of the medical staff, while patients who had completed treatment felt more uncertain about the success of their treatments, the predictability of their physical symptoms (e.g., the timing and intensity) and the meaning of

¹³ By contrast, in her excellent research on self and time in illness, sociologist Kathy Charmaz (1992) offered a different perspective: “several young adults had fluid, rather unstructured lives...Having few time pressures, their lifestyles and time perspectives muted the effect of intrusive symptoms” (p. 58-59).

their pain (e.g., if it signified a recurrence or chronic effects). Decker et al. argued that new patients' concerns originated from the alienating experience of being "thrust into the unfamiliar environment of an oncology center" (p. 684), which entailed a complex of new interactions (e.g., with health professionals), new roles and responsibilities (e.g., attending frequent appointments), and a new language (i.e., medical terminology); later on, other fears emerged as check-ups became less frequent, patients lost contact with healthcare providers, and medical oversight of their health tapered off—in other words, a second alienation from a medical world that had become familiar and routine. Emerging and changing fears as a result of unhomelike experiences are seen to prolong the disruptions of cancer long after it has been treated, thereby having an indefinite interference with young adults' developmental tasks.

The purported stakes of young adult cancer seem to revolve around a host of perceived psychosocial outcomes: adjustment to life with a chronic illness, satisfaction with body-image, identity development, putting aside morbid thoughts about death, 'mastering' life tasks like sexual intimacy, etc. (CIHR, 2009; Decker, 2006; Ettinger and Heiney, 1993; Gavaghan and Roach, 1987; Woodgate, 2005). In response to the potential dangers of cancer on developmental 'success,' a variety of interventions have been proposed that focus on maintaining social connections with peers; providing information/counseling on familial, reproductive, and health issues; ensuring 'mastery' of developmental tasks; boosting self-esteem; and reorienting patients toward future (family and career) goals (D'Agostino et al., 2011; Ettinger and Heiney, 1993; Nathan et al., 2011; Odo and Potter, 2009; Rowland, 1990; Woodgate, 2005; Zebrack, 2008). The prevailing, and quite problematic, directives of these interventions may be summarized thus: "Ultimately, the goal of supportive care for AYA with cancer is to facilitate their achievement as self-reliant, independent, and productive members of society" (D'Agostino et al., 2011, p. 2333).

There seems to be a growing literature on young adults' concerns, particularly on age-sensitive struggles, possibly signaling the construction of an AYA oncology sub-field. In some ways health research is heading in a praiseworthy direction, taking stock through interviews and surveys of young adults' major biographical and existential challenges. On the other hand, much of the literature shares a serious limitation: age is often seen as important only insofar as it relates to essentialized 'developmental tasks' of young adulthood. Much of the literature employs sweeping generalizations—in their efforts to reveal the distinct psychosocial concerns of young adults—that blind readers to the plurality of life histories that lead to multiple trajectories of young adult life¹⁴.

Exaggerated or uncritical assertions are tossed out without providing rigorous analysis to defend them; for instance, that AYAs harbor “a perceived invulnerability and a growing desire to be autonomous” (McGoldrick et al., 2011, p. 2312). For the most part absent of young adults' own voices, many of these publications appear to presuppose young adults' desires and projects. Considering that there may be a “new timetable for growing up” (Furstenberg, 2010) not necessarily following the narratives and practices of the 'traditional milestones,' we have to wonder why they are so strongly affirmed within young adult oncology.

What is lost in this normative approach is consideration of what young adults find significant within their local social worlds, which may be gleaned from their stories of cancer. It is possible that they may have very different ideas about where they are in their lives and where they want to be and, therefore, they may have dissimilar 'developmental tasks' that are desired, pursued and/or frustrated while living with cancer. In some circumstances, young adults may not narrate their changed bodies, destabilized identities, or reliance on parents as failures, but rather

¹⁴The same may also be said of many representations of cancer patients irrespective of age. At the very least, it is often the case for older people with cancer as well (see e.g., Hammond et al., 2012; Sinding and Gray, 2005; Sinding and Wiernekowski, 2008).

as fodder for seeing new life possibilities (e.g., advocacy for other young adults, deeper appreciation for their families, etc.).

The question is not whether there are alternative meanings, ways of being, and trajectories, but how we judge narratives of such scenarios in relation to normative expectations. Do they mark a failure to achieve ideal young adulthood? Arrested development? Deviant or maladapted subjects? Meaningful and gratifying projects in their own right? Marginalized lives in need of legitimation? These are serious questions about individual narratives of disruptive or alienating experiences interact with ideological perspectives, questions to which I do not believe much of the psychosocial research on young adult cancer answers sensitively or critically.

2. A Critique of Developmentalist Discourses

Young adults' age-specific concerns are perhaps partially dependent upon social and material conditions, as well as personal and cultural expectations around significant life events and rites of passage (e.g., Kelly et al., 2004; Rowland, 1990; Zebrack, 2011). I question the above discourses in terms of their visible lack of critical and contextual considerations of young adulthood, for instance: that development can be thought of as negotiated identities and may thus place less normativity on task achievement; that economic recessions can make financial independence and independent living less feasible and perhaps even less desirable (risky as it can be); that a lot fewer people in North America are following the 'traditional cycle' of adulthood than even 30 years ago; and that modern technology has possibly enabled the emergence of multiple local and global identities. In sum, how the majority of young adults talk about and experience psychosocial development may be changing dramatically from how it is represented within oncological discourses.

The reviewed literature and the discourses they perpetuate construct relatively few life paths as being desirable, thereby normalizing certain trajectories to the neglect of other equally meaningful ways of living. Some propose, like radiation and medical oncologist Simon Sutcliffe (2011), that there is a “multiplicity of medical, social, and psychological challenges for AYA cancer patients,” that we need “cultural and contextual perspectives on the provision of AYA oncology care,” and that “a single solution is unlikely to fit all situations” (p. 2244); yet, this commentary is hardly ever offered let alone elaborated upon. While some researchers reflect on the “social, financial, and cultural resources” available to young adults (e.g., Grinyer, 2007, p. 266), they evaluate such contexts only according to whether they enable or impede achievement of the aforementioned developmental tasks.

This general criticism could go in a number of specific yet interconnected directions regarding the failures of ideological discourses to account for hidden or unsanctioned meanings and ways of being among young adults. For example, heterosexist assumptions pervade talk about AYA patients’ sexuality without consideration of the fluidity and multiplicity of sexual orientations and practices (e.g., Diamond, 1998). Also, the goals of self-reliance, independence, and productivity fall within what some would say are capitalistic expectations of accumulation of wealth and property that marginalize, among many others, dis-abled or other-abled people who do not meet those demands (e.g., Oliver, 1998, 1999)¹⁵. Finally, patriarchal discourses of femininity are implicit in efforts to preserve and encourage fertility among young women patients, even though quite recently many women are choosing voluntary childlessness (e.g.,

¹⁵ Importantly, the current recession and housing market bubble has possibly minimized desires for property ownership, signifying yet another possible cultural shift in values and identities. For example, in a 2013 interview for the CBC radio show *The Current*, Queen’s University professor of environmental studies and business John Andrew noted that home ownership is increasingly becoming unfeasible for most younger Canadians. In turn, he reported shifting attitudes among young adults from assuming “you’re not successful in society unless you own your own home” to thinking it is “much more attractive to be a renter long-term, perhaps never buying your own home.”

Gillespie, 2000). These ideologies do not just fail to capture certain ways of being; they create “deficit models” that judge different ways of being as failures to achieve a singular ideal (Rogoff, 2008, p. 16).

Allow me to expand upon two illuminating counterexamples of the dominant research on AYA patients. With regard to family plans and sexuality, fertility is often presumed to be an issue all young adults care about (e.g., List et al., 1991; Nathan et al., 2011); however, in a study conducted in Britain, social worker Marilyn Crawshaw and colleagues (2009) reported that adolescents and young adult patients actually had mixed responses to finding out they may have troubles with infertility. A marginal majority of patients were deeply impacted by the loss of reproductive capabilities, while a large minority said they were more concerned about surviving than about fertility or were simply not interested in parenthood. They observed “there were clear differences in reactions among participants who shared a chronological age and might be seen to be at a similar life stage” (p. 387). They concluded there is a “need to be alert to the unique meaning of fertility to the individual concerned” (p. 388).

Crawshaw and colleagues also found that patients varied in the extent to which they wanted to involve their parents in their decisions about fertility services, which raises questions about young adult independence. To what extent do young adults want to rely upon their parents while living with illness? What kinds of (in/ter)dependence are desired? Such questions are rarely raised in the research. Many articles present increased dependence upon parents as a burdening “stress” on both parties (e.g., Ettinger and Heiney, 1993; Pritchard et al., 2011), even as an unfavourable and “infantilizing” “regression” to earlier family dynamics (e.g., Kellerman and Katz, 1977; Odo and Potter, 2009; Tonorezos and Oeffinger, 2011). Yet, among some qualitative research with AYA patients, issues of independence and choice seem to be a great

deal more complicated, bringing some positive and some negative changes to how patients see themselves and their families (e.g., Crawshaw et al., 2009; Kelly, Pearce, and Mulhall, 2004).

Perhaps we should not be so hasty to label dependence or other ‘deviations’ from normalized pathways as an inevitable threat to young adults, but instead ask ourselves and ask patients what family involvement means to them. Most importantly, we need to critically evaluate what ‘independence’ means for patients (as the literature is quite vague on the concept to begin with). The two British studies above, though admittedly small in number and limited in generalizability, should give pause to the assumption that young adults place similar meaning and importance on family planning and independence, at least within the context of living with cancer.

In sum, this research raises questions about the differential relevance of the ideology of young adulthood. There is hardly any sense in the literature that these issues carry varying degrees of significance for people at different points in their lives—a sensitivity anthropologist Michael Jackson (2005) summarized in the following assertion: “being is never an ‘either/or’ thing, but a ‘more or less’ question” (p. x). While certain modes of being are essentialized within these discourses—parenthood, marriage, financial security, independence—these modes may retain different levels of relevance both between different people’s stories and over time within a single person’s narrative. With all these discourses of developmental ‘tasks’ and social ‘roles’ (e.g., D’Agostino et al., 2011; Zebrack, 2011), little room left for conversations about ‘meanings’ and ‘praxes,’ which get us thinking about situational desires and needs: In what ways do young adults reevaluate what they find meaningful in life as a result of having cancer? In reflection, what tasks are considered fundamental to their senses of meaning and being, which are simply seen as hoops to jump through, and which have no currency in their lives whatsoever? In other

words, how do people live out in meaningful, sometimes critical, ways the expectations of young adulthood when their pre-conceptions may be threatened, foreclosed, or stripped of value by illness?

Age in itself does not determine people's most pressing concerns. Developmental researcher Bernice Neugarten (1987), for instance, believed that "age has become a poor predictor of the timing of life events, just as it is a poor predictor of health, work status, family status, interests, preoccupations, and needs" (p. 74). Instead of reifying age-specific concerns, it is better to look at how individuals relate to dominant identities, meanings, and values within their narratives. For instance, critical gerontology argues that, contrary to dominant discourses of aging as a time of decline, there is no singular trajectory either of aging (Friedan, 1993; Gullette, 2004; Randall and McKim, 2008) or of aging during illness (Hammond et al., 2012; Sinding and Wiernekowski, 2008; Towsley, Beck, and Watkins, 2007). In her research on midlife experiences, developmental psychologist Margie Lachman (2004) asserted that we need "multiple conceptions" of development to account for their "diverse trajectories" (p. 313). Extending these approaches to young adults with cancer, health researchers may be challenged to consider the cultural diversity of meanings and ways of being across different people.

Cultural diversity goes beyond alleged differences between two predetermined groups (e.g., Caucasian patients and First Nations patients, young adults and older adults, men and women). Culture, according to anthropologists Arthur Kleinman and Peter Benson (2006), "is not a single variable" that can be reduced to, say, ethnicity or age group, but rather is "inseparable from economic, political, religious, psychological, and biological conditions...through which ordinary activities and conditions take on an emotional tone and a moral meaning for participants" (p. 1674). If we try to account for at least some of these factors

in interaction (it is a daunting if not impossible task to incorporate all), we may find that people within the same age, gender, ethnic background, political stance, socioeconomic status, geographical location, religious community, and family tell very different stories about their experiences. Such is a potentially fruitful strategy for studying young adults' lives.

For my part I wanted to conduct a general, explorative investigation into the unrecognized diversity of young adult meanings and ways of being expressed within narratives of cancer. At the beginning of the first chapter is a cited plea from writer and cancer patient Kairol Rosenthal to study the “complexity” of young adult life. I see very little effortful practice within psychosocial oncology of locating young adults within the social, cultural and historical frames that would richen our representations. It seems ironic that McGoldrick et al. (2011) cite Margaret Mead as an inspiration for their work with younger patients, as her book *Coming of age in Samoa* (1929/1963) radically challenged universalist ideas about the adolescent stage of life. This consideration could be feasibly extended to young adults as well, and the diversity seen among the general young adult population may be even further multiplied by the various physical, psychosocial, and existential changes that life with cancer can instigate.

3. Individual Responsibility for Illness

Going beyond developmental tasks but still within the prescriptive framework of independence or self-authorship, many of the discourses around young adult cancer perceive it to be a matter of personal responsibility. Not your typical understanding of ‘patient-centred care,’ illness is often individualized as a matter of personal ‘issues’ rather than social tensions like isolation from others, stigma around certain illnesses, and physician-patient conflict; or structural restrictions like discrimination, an overburdened healthcare system, or inaccessibility of proper treatment (see e.g., CIHR, 2009; McGoldrick et al., 2011).

Risk factors requiring intervention are predominantly related to personal lifestyle (e.g., diet, exercise) while social-environmental factors receive very little attention (see e.g., CCS, 2006; CCS, 2009; Riley, Manske, and Cameron, 2011). The latter would include larger socio-political issues such as racism within the clinic, air and water pollution, and, as Arthur Kleinman (1996) observed, poverty as a predictive indicator for morbidity and mortality. Cancer is often constructed as an individual *disease*, not as a socially related *sickness* that may have both social causes and effects (Kleinman, 1988). Lung cancer may be seen as an example as it may develop from airborne carcinogens including first- *and* second-hand cigarette smoke as well as asbestos, naturally occurring radon gas, and cooking oil vapours (Sun, Schiller, and Gazdar, 2007); despite the limited control people have over what they breathe it is often stigmatized as a self-inflicted disease (Chapple, Ziebland, and McPherson, 2004). Attention to patient individuality should not mean that intersubjective factors to health and illness are ignored or ruled out.

Intervention programs are also usually geared toward individual adjustment instead of community support such as social recognition and reduction of stigma, or political change such as advocacy for better awareness, access, and care (CCS, 2006; CCS, 2009; CIHR, 2009; CPAC, 2011; Nathan et al., 2011). McGoldrick and colleagues (2011) see “empowerment” of young adults as teaching them to “take responsibility for their own health and wellness, encouraging regular checkups and screening, as well as educating them on lifestyle choices and behaviors, focusing on management of exposures to known carcinogens as well as environmental and occupational health hazards” (p. 2313); in other words, placing the burden of prevention on individuals. This may be seen as a form of self-surveillance that can indeed improve some outcomes (e.g., breast self-exams may lead to earlier detection), but lends itself to assuming illness is predominantly under individual control and blame. Young adults’ cultural practices are

reduced to either ‘healthy’ or ‘unhealthy’ lifestyles, with the route to better outcomes paved mainly by patient labour.

Let me illustrate an important example for my research. One of the identified reasons young adults have relatively poorer outcomes is that diagnosis of their cancer are often delayed for longer periods of time, allowing accelerated growth and metastatic spread of their tumours (CCS, 2009; CIHR, 2009; McGoldrick et al., 2011). There may be many explanations for why this is happening, but the issue tends to be boiled down to patient non-compliance and resistance to seeking medical attention (CCS, 2009; CIHR, 2009; McGoldrick et al., 2011). This assumption flies in the face of many young adults’ stories—and there are many, as we will see in following chapters—of seeking medical attention for symptoms and not being taken seriously because their physicians held preconceptions that young adults don’t get cancer. It is perhaps ironic that often the problem lies with heavy reliance upon incidence rates, which show that young adult cancer is statistically very rare. The very “technology of presencing” (Jain, 2007) used to argue young adult cancer is an important health issue can also be a technology of “absencing,” serving to conceal young adult cancer because of its statistical insignificance.

Very rarely is it expressly acknowledged that faults in earlier diagnosis and better outcomes may be partially due to a lack of knowledge and understanding on the part of practitioners (for some exceptions, see Barr, 2011; Gafni, 2011; Ramphal et al., 2011). Social and structural barriers within medical institutions can be so pronounced that some patients find the biggest challenge in cancer care is simply being heard. In one of Kairol Rosenthal’s (2009) interviews with young adult patients, one person who was attuned to this struggle said, “Don’t fight the cancer, fight the people who get in the way of you receiving the best care possible” (p. 236), recalling how his healthcare team was sometimes a barrier to his recovery. ‘Self-advocacy’

has become a buzzword among many younger patients who see cancer as a partly political process of conflict and negotiation with their care providers. Unfortunately, this local politics of cancer is concealed by discourses of individual responsibility and adjustment. Along with finding ways to encourage regular medical checkups and treatment compliance among young adults, attention should also be drawn to the barriers that “get in the way of” young adults seeking medical treatment.

4. Conclusion: The Need for Localizing Meaning and Being

Dominant psychosocial discourses within young adult oncology seem to emphasize task-based theories of development and patient-determined outcomes, repeating broader cultural assumptions that young adults become authors of their lives and perform certain predefined rites of passage into ‘adult’ identities. Informative of some of the stakes and existential challenges of illness, these discourses direct attention away from a) the diverse ways in which young adults may talk about ‘development’ in negotiation with the conditions of life set out by having a chronic illness, and b) young adults’ perceptions of barriers to and factors involved in healing beyond assumed personal negligence of their health. In response to these limitations, there need to be programs of study placing psychosocial issues of illness within local social contexts of meaning and being. My purposes within this research project were to bring such a program into a narrative analysis of young adults’ stories of cancer, to which I refer to in the following concluding paragraphs.

Chapter Conclusion: A Critical Narrative Program of Cancer Research

Dominant biomedical and psychosocial discourses generate the above representations of young adults, which may be used by oncologists, nurses, patients and families alike in order to drive social and political change within healthcare. By no means should they be construed as

intentionally malicious or violent discourses, adding no merit or value to conversations about young adults with cancer. The purpose of my critical analysis of the literature was to show not the harms that are intended by such discourses, for I am sure the very best of intentions drive their usage, but rather their implicit, hidden, yet inferable conclusions and effects, the unintended violence to young adults' ways of understanding and living.

We saw within this chapter a repetition of more general discourses already identified in the first chapter as problematic: the medical Cartesian assumptions about the reduction of bodies to biology; the separability of bodies from minds with priority given to cure of disease over care of the lives affected; and the isolability of people from their local worlds, leading to prescriptive claims about developmental tasks and individual responsibility. The social and phenomenological sides of illness tend to get lost in medical Cartesianism, which may lead to marginalization of young adult narratives that do not follow the normative 'trends' or fit into the subjects constructed by these discourses. One way to bring forth these hidden meanings and ways of being is to enter the worlds constructed within young adults' stories and critically evaluate how they repeat and how they resist dominant discourses.

A few studies of young adult cancer have already employed narrative techniques, but rarely does this research go beyond the normalizing discourses I have critically evaluated within this chapter. Health researcher Anne Grinyer (2007), for example, showed an unreflective affinity to 'normal' trajectories of young adulthood, as when she argued, "Anything that contributes to the maintenance of normality must be welcomed, and fostering a continued connection to youth culture and the 'normal' activities undertaken by young people is valuable" (p. 274). A critique of discourses, especially around what is normal, seems unfortunately absent in her proposed solution to the unhomelike being of young adult cancer.

Critical study of illness narratives has a fringe but strengthening tradition within the health sciences. Among the strongest proponents of narrative research in clinical practice are psychiatrist Arthur Kleinman (1988) and physician Rita Charon (2008), who argue that narratives can bring to light patients' stakes within their social worlds, cultural assumptions, and politicized discourses. A narrative agenda may restore attention to the larger contexts of patients' needs and experiences. In my own studies, narrative analysis provided an interpretive frame for questioning embedded assumptions about young adulthood and the effects of cancer, and making sense of how meaning and being are negotiated within situations of illness. In the next chapter, I outline the methodological as well as philosophical details of the narrative approach adopted for my dissertation.

Perhaps within young adults' voices, within their stories of cancer, we may hear dissent, contradiction, and resistance to the above discursive constructions—even alongside affirmations and reiterations of developmental tasks, individual responsibility, and the like. My call for critical research into young adults' stories does not mean we do away with any thought of age-specific experiences and concerns; quite the contrary, we look into the wide spectrum of ways these assumptions are engaged, from reification, adaptation, and evaluation to opposition.

A Crisis in Illness Representation?

“The academy has long rewarded readings that dismantle literature’s illusions but, with regard to literary and amateur illness memoirs, it is also evident that critics need other options, interpretive approaches that enable them to assemble meaning in the face of life’s fragility.”

—Anne Jureric, *Illness as narrative*, p. 4

Introduction

In a short presentation at the International Congress of Qualitative Inquiry, psychologist Kenneth Gergen (2012) spoke to a crowded audience about competing and seemingly irreconcilable modes of interpretation within the discipline, between more suspicious, critical analyses of human expressions and more empathic attempts to understand the perspectives expressed on their own terms. He was not talking about illness narratives *per se*, though his words rang resoundingly true for me in my work. Dr. Gergen pined for a time when these vastly different modes of interpretation could be synthesized within his own mind and many of us nodded in admission of having similar wishes every so often.

Dr. Gergen seemed most concerned about what is often called a ‘crisis in representation,’ in this case a perceived failure between psychologists to agree on what human expressions *symbolize* or *represent*. How should we evaluate the actions and stories of others? In place of a consensual ideal, there is endless dispute, contention, and downright antagonism at times about the ‘right’ reading or analysis. This issue of ‘how to represent’ may be more inflamed and convoluted than I present it below, but I introduce it to bring home a more specific and relevant point: illness narratives are not exempt from these interpretive tensions in the human sciences.

This is, of course, very pertinent to research projects that have expressions such as narratives as their unit of analysis.

Beyond this particular point, I share my basic theoretical orientation and methodological practices in this chapter. I continue on from the previous chapter about the need for narrative study of young adult cancer experiences. In light of a possible “crisis of illness representation” (Good, 1994) I show support for critical phenomenology, a theoretical perspective intended to straddle and converse between different traditions of evaluating narratives. From there I share some philosophical assumptions about the nature of human reality and knowledge that I infuse into my theoretical perspective. In a final section on the research process I explain narrative analysis as an applicable methodology for pursuing a critical phenomenology of young adult cancer, before summarizing the methods used in my study for gathering, conducting, and analyzing illness narratives.

The Double Motivation of Modern Hermeneutics

Sentiments of a crisis in representation are not unique to psychologists; every scholarly discipline has its opposing perspectives and contradictory evidence. Indeed, the particular impasse that Dr. Gergen regretted in psychology is one shared by all of the human sciences, from sociology to literary theory. Philosopher Paul Ricoeur (1970) saw these disciplinary conflicts as a pervasive plight of modern interpretation theory: “there is no general hermeneutics, no universal canon for exegesis, but only disparate and opposed theories concerning the rules of interpretation” (p. 26-27).

I do not mean to suggest interpretive dispute is a recent phenomenon. Even the ancient Greeks argued vehemently over how to evaluate people’s stories. Plato (1956) wrote in Book X of *The republic* that many artistic representations—including paintings, drama, poetry, and the

like—are “imitator[s] in the third generation from nature,” that is, they are based on “appearances” that are themselves loosely based on their true, ideal Forms (p. 393-397). Though Plato found art forms like narrative veritably useful in the production of dialogue¹, he subordinated the former to the latter in the pursuit of truth.

On the other hand, Plato’s own pupil Aristotle held art in higher regard. In *Poetics* (1987), he saw a dual power in all stories. The first is their ability to capture transformative moments, the grist of lived experience², with the most notable examples being the changing life circumstances in *reversals* of fortune and coming to knowledge in *recognitions* of some hidden or unknown state of affairs (p. 14-15). Secondly, through metaphoric, ornamental, or unfamiliar uses of words, stories can not only articulate what *is* in life, but also what *may be* (p. 35-37). Illness narratives, for instance, postulate and explore multiple possible realities (Good and Delvecchio-Good, 1994) through, for example, at one time referring to life with cancer as a ‘battle’ and at other times as a ‘journey.’ Subjunctive mood is a form of narrative voice that entertains diverse futures (Good and Delvecchio-Good, 1994; Turner, 1986, p. 42).

Though somewhat disparate, the different islands of interpretation may be grouped into two sides. Ricoeur (1970) described what he saw as the “double motivation” of modern hermeneutics: a “willingness to suspect” informed by skeptical enquires into the falsities of expressions, and a “willingness to listen” informed by phenomenological enquiries into their illumination of lived experiences (p. 27). Philosopher of science Michael Crotty (2003) placed these dual motivations within the robust traditions of *critical* and *interpretive* analysis, with the former exposing ideological layers of cultural meaning within a “battleground of hegemonic

¹ For example, Socrates often engaged Greek myths in order to advance dialogues with his interlocutors from sophistic to more logical reasoning.

² This argument, which I unpacked in chapter 1, has informed much of contemporary interpretive psychology and anthropology (see e.g., Bruner, 1986; Mattingly, 1998; Turner, 1986).

interests” and the latter “uncritically”³ interpreting cultural meaning within a “peaceable” world of interactions (p. 60-63).

Despite the historical endurance of scholarly disagreements around representation, certain debates are accentuated in contemporary human sciences. Let us look briefly at some of these different perspectives, starting with those sharing a willingness to suspect.

Current Critical Traditions of Analysis

More recent critical traditions of the last three centuries spend less time evaluating the limits of the medium—the perceived inferiority of art for finding truth, as Plato saw it—and more time noting the *many prejudices of the messenger*. The legacies of Karl Marx, Friedrich Nietzsche, and Sigmund Freud share suspicion over the ‘falsity’ of consciousness, ignorant of its own material conditioning, drive for power, or unconscious urges (Ricoeur, 1970, p. 32-33).

Through a psychoanalytic lens, literary theorist Elizabeth Bronfen (1992/2000) saw all narratives as “fictions” that “serve to negate reality, to repair or mitigate one’s own destructive impulses and patch up wounds to one’s narcissism” (p. 193). Behind texts she saw authors seeking psychological consolation and narratives strictly functioning as a means toward that end. Some recovery stories of illness, for example, young adult writer Erin Zammett’s (2005) published memoir, contain a patent optimism and hopefulness that could be interpreted as a survivor’s bias. Death, a subject of immediate concern to many cancer patients who have not reached a state of remission, is notably absent within Zammett’s story and may more closely represent her appeased state of mind while writing than the prevalent feelings she encountered

³ I do not think Crotty meant that interpretive traditions lack critical thinking, but rather they bestow a “postcritical” trust in language as a disclosing medium of meaning (Ricoeur, 1970, p. 28).

while in the midst of diagnosis and treatment⁴. The scholar's duty, from Bronfen's perspective, is to expose these mechanisms of self-justification that underlie a story's composition.

From a different angle, Hayden White (1981) proposed that underlying all narratives (historical or fictional) is a human impulse to "moralize reality" (p. 14). In particular, White insisted that narratives lead audiences to believe that the world can "speak for itself," when in truth narratives make the world appear in unison with authors' moral expectations. A more obvious example of this is young adult Kris Carr's (2007) *Crazy sexy cancer tips*, partially a mix of memoirs from different cancer patients and partially an instructive guide for how to 'beat' cancer. Though the tone is relatively forgiving, the content implies that with a strict diet, exercise program, positive thinking, and related activities of 'self-care,' cancer can be cured. Behind these claims are moral constructions of healing revolving around cultural notions of individualism, personal responsibility, and psychosomatic medicine (see e.g., Ignatieff, 1987; Stacey, 1997).

These narrative 'advertisements' for certain care practices are, again, retrospective accounts written from a position of remission. That one event (e.g., drinking an organic vegetable shake) preceded another (e.g., remission) does not necessarily prove a causal relation and may instead lead to what in philosophical logic is called the *post hoc ergo propter hoc* fallacy (Latin for "after this, therefore because of this"). Moral expectations and cultural assumptions may fill the gaps between past and present, and conceal leaps of logic in stories of recovery. It may be argued from this perspective that counter-narratives are needed to balance out morally weighty depictions of the world, and it is the job of the narrative critic to provide these against-the-grain interpretations.

⁴ In the spirit of the interpretive crisis, many other explanations for this absence are not only plausible, but may even complement a psychoanalytic reading: publishers' requests to tone down the gloom in Zammatt's narrative; social pressures to censor stories that may evoke anxiety in some readers; genuine absence of death awareness during her illness experience; and many others.

Finally, post-structural literary theorist Roland Barthes (1966/2000) insisted that there is no “final meaning” to a text that could lend itself to reality, the varied paths of meaning cannot be “deciphered” but only “traversed,” and that assigning an authority to a text serves only to “impose upon that text a stop clause” (p. 4-6). Let’s return to Zammett’s optimistic attitude, which could be seen as a “final meaning” plugged in to stop the emotional currents of uncertainty while living with cancer. There are moments in her narrative where she breaks down and starts crying, but the scene is hastily cut off. As critical readers we may see these as “signifying traces” (Derrida, 1967/1976, p. 23) of other attitudes, other meanings, in this case possibly fears of death, shimmering cracks in the curtains separating audiences from behind-the-scenes. Through a deconstructive reading, post-structuralists may defuse the laborious work of narratives to seize the unending pulse of life and meaning.

Current Interpretive Traditions of Analysis

There are also more charitable interpretive traditions today, in which narrative is lent more trust and truth. Narratologist Gerald Prince (1990/2000) suggested we ought to consider the etymology of the word narrative (the Latin word *gnarus* meaning “knowing” or “acquainted with”), which implies narrative is didactic in some sense, revealing some truths about human life. According to physician David Kuhl (2003), illness narratives may offer “practical wisdom” about deeply existential matters of living with and overcoming suffering. The published young adult narratives of Zammett and Carr may be read with eyes for what Ricoeur (1970) referred to as “revelation,” an openness to discover something illuminating from the words of another. In this perspective, their flippant attentions toward death and dying speak true of something about young adults’ experiences of illness, perhaps their proclivities to see illness as more of an

“interruption” than an “intrusion” (Charmaz, 1992, p. 58-62), perhaps, more broadly, their obstinate optimism toward life (see e.g., Savage et al., 2006).

Modern interpretive traditions, according to Ricoeur (1970), dispute Aristotle’s assumption that representations hold a “univocity of meaning” (p. 23), arguing instead that *meanings are richly plural and diffuse* depending on the audiences, circumstances, and literary forms of a story. Many of the interpretive traditions in the human sciences today are heavily influenced by phenomenological methods and hermeneutic perspectives (Polkinghorne, 1983; Ricoeur, 1970). In terms of phenomenology, a pervasive assumption is that in any expression, including narrative, there is “something intended” or signified (Ricoeur, 1970, p. 29). That which is signified is both literal in that people mean what they say and symbolic in that metaphors, metonyms, tropes and other poetic uses of words signify more than what was said.

The richness of expressions holds the potential for misunderstanding and miscommunication. Ricoeur (1988) made a convincing point: “The ‘right’ reading is, therefore, the one that admits a certain degree of illusion...and at the same time accepts the negation resulting from the work’s surplus of meaning, its polysemanticism, which negates all the reader’s attempts to adhere to the text and to its instructions” (p. 169). In his narrative of advanced cancer, literary critic Anatole Broyard (1992) noted, “what a critically ill person needs above all else is to be understood. Dying is a misunderstanding you have to get straightened out before you go” (p.67). This can be tricky as “the sick man sees everything as metaphor” (p.7) and it may be hard, perhaps impossible, for listeners of illness narratives to catch the scattered signs and associations shooting off in different directions. Many interpretive researchers enter into the jurisdiction of hermeneutics—theories of interpreting symbolic gestures—to help them negotiate the “surplus of meaning” with their limited capabilities to understand the expressions of another.

Though ‘revelation’ may be the express goal of this form of hermeneutics, narratives are still seen within interpretive traditions to be constructions based on unconscious, ideological, and/or dominant cultural modes of organizing life stories (Good, 1994, p. 144-146). The same person may tell very different narratives of his or her cancer depending on the situation and audience. However, instead of ruling that narratives are therefore false, interpretive traditions look more benignly, sometimes even exultantly, on the constructive elements of narrative. Some may see a provisional and pragmatic order being produced in narration and serving certain demands of a situation aside accuracy, such as making the account more intelligible to others and providing instructions for action (Kleinman, 1988, p. 49; Rimmon-Kenan, 2002, p. 15). For instance, people seeking a diagnosis and medical intervention of their pains, lumps, and bleedings, may tell stories they believe will spur on health professionals to become concerned and provide care.

Taking into account expediency, bias, coercion, and other editorial factors, most interpretive traditions argue narratives produce *a* reality among *many*, what Paul Ricoeur (1988) called a “virtual experience of being-in-the-world” (p. 100). ‘This’ story, told at this time and to this group of people, may not be the ‘whole’ story, but contemporary hermeneutics harbours more doubt about the existence of a singular account of experience. The prevailing assumption is that narratives do not correspond uniformly to the reality of lived experiences, but construct new realities that broaden understanding of what happened. In some sense, as sociologist Arthur Frank (1995) put it, “The truth of stories is not only what *was* experienced, but equally what *becomes* experience in the telling and its reception” (p. 22; original text).

The above review of critical and interpretive analyses should demonstrate that scholarship of narratives is torn between an itching desire to question people’s claims to

authenticity and a sympathetic concern for hearing them out. Divisions between these different approaches has only deepened and widened over time, now appearing as an archipelago of theoretical positions separated by dark, chasmal waters.

The Crisis of Illness Representation

Some scholars have written about how this crisis of modern hermeneutics has affected *illness* representations in their own discipline. For instance, Byron Good (1994) wrote about the frequent “juxtaposition of ‘critical’ to ‘clinical’” positions in his home discipline of medical anthropology (p. 59); while the former often interpret illness narratives as the products of oppressive social structures and self-deceptions, the latter typically develop phenomenological accounts of illness from within the perspectives of the ill. The two camps tend to fight between each other for interpretive authority over their subjects of enquiry. Ann Jureric lamented that literary studies of illness also suffer from critical divisiveness: “On one side stands the dispassionate critic who is suspicious of art that elicits sympathy or empathy; on the other is the empathic critic who seeks to acknowledge the suffering bodies at the center of art” (p. 13). Across many disciplines that study illness are these interpretive polarities.

I do not quite agree with Jureric’s implication that the polarities are between people of different ‘sorts’ or personalities. The sense I get from Drs. Good, Jureric, Gergen, and many others is that the tensions between suspicious and empathic interpretations are keenly felt within themselves. It is not a matter simply of different ‘camps,’ where a like-minded group is tenting away from ‘those other guys.’ Conflicting readings is a matter also of individual interpretation, when one is caught between seemingly irreconcilable assumptions and conclusions. The incessant drum of competing voices is both a public and a private tension. I feel the tantalizing

lure of different perspectives, which all make sense on some level as I listen to (or criticize) stories of cancer. That is what strikes me most about the alleged crisis of illness representation.

Furthermore, the modes of action instructed by different perspectives hold varying sway for me as time passes. As a case in point, my default position is that young adults' stories just need to be heard and acted upon on their own terms, and all will be well. Yet, in moments of working against-the-grain, I begin to think that what could benefit many young adults most is tearing away their assumptions of entitled longevity, a contradiction that seems to be among the most devastating to people who are recently diagnosed. These and other moments of self-doubt transform the general crisis in illness representation into my crisis in representing young adult cancer narratives.

A Philosophical Perspective on Illness Representations

Singularizing Hermeneutics of Illness

From my perspective the primary problem of the crisis of illness representation is not its consequences for the status of academic knowledge, disrupting efforts to attain a singular, higher-order, or regal form of understanding. No, my concern over the crisis is the discomfort and intolerance many scholars—including myself—feel toward it at times. Often enough, perspectival diversity may be seen as anathema to a social science within which a unified Truth is held as ideal. Research can be a political and ideological affair where scholars take 'sides' and toss heckling shouts of hostility across the floor at the 'opposition.' In his historical review of different schools of thought, psychologist Donald Polkinghorne (1983) observed that as long as disagreement has existed between interpreters (and he traces modern hermeneutics to Catholic and Protestant disputes over biblical exegesis), an ideological unity of interpretations has been attempted among those who are most discontent with difference of opinion (p. 219).

The danger of such an effort, from my view, is that human life in general and illness experience in particular is much richer than a unified theoretical orientation can afford. Intellectually I see theory in this toned-down light, but I am still caught up sometimes in statements of certainty. Nevertheless, I try not to sever the pull from one side, knowingly forsaking my own doubts in an effort to finalize my own perspective as ‘critical’ or ‘interpretive.’ On a more socio-political level, philosopher Odo Marquard (1981/1989) argued that working toward a final interpretation, what he called a “singularizing hermeneutics,” can lead to a “hermeneutic civil war” if pushed to the brink (p. 122-127). Such was the case, he claimed, with the Thirty Year’s War, in which Catholics and Protestants killed each other over unaccepted interpretive differences (p. 122). Disputes of interpretation do not just remain in the clouds of lofty reflection but can plummet to the ground of embodied life and wreak havoc.

Not to say that I expect a divided discipline will lead to a riot between misguidedly zealous scholars. The violence need not be a literal battle of arms, but a harmful breakdown of conversations, a collective refusal to share knowledges and perspectives. More importantly, a rigid reading of people’s lives can produce disastrously simplified images of illness experiences, marginalization of unrecognized voices and social locations, and an aloof ignorance of people’s pain, all of which are forms of interpretive violence⁵. Kleinman and Kleinman (as cited in Whyte, 1995), observe this danger as a crucial “challenge...as social researchers; any rendering of human experience as a category (e.g., medical diagnosis, social role, symbolic gesture) threatens to dismiss distress on its own terms” (p. 283). Byron Good (1994) wrote that “illness is all too real” and treating patients’ stories as analogous to fictional novels, as critical schools are

⁵ Philosopher Jacques Derrida (1980/2000) pointed out that it can be dangerous to simply call on a person to *recit* (“give an account of”) serious illness, for suffering can actually escape “an objectifiable topology or chronology” (p. 223). From my perspective, the violence of imposing form on formless experiences is an ever-present possibility, neither fully avoidable nor fatally inevitable, but at least made visible when we speak openly about the limits of our understanding.

wont to do, can “devalue suffering and misrepresent the very essence of the experience” (p. 163). Directions toward a dogmatic or unified reading, especially a suspicious reading, of illness narratives do not promise recognition of illness as a *real* and *complex* experience of suffering worthy of our care and compassion.

Within the humanities, Jureric (2012) provides an important example of the limitations to a singularizing hermeneutics. She wrote concernedly of the dominance of critical theory within literary studies of illness narratives. She observed that many literary critics, rightfully so, keep in mind that stories of illness are “constructed by medical discourse and political, economic, and cultural forces” and that the uncritical reader is susceptible “to the myriad powers of dominant discourse” (p. 3). Problems emerge when the whole of the work is consumed by these considerations. Although critical theory has historically endeavoured toward empowerment, it may ironically disenfranchise people seeking recognition of their anguish. Jureric referred to dance critic Arlene Croce’s paper “Discussing the undiscussable”⁶ as part of a larger trend of boiling down artistic expressions of pain and illness into cheap ploys for political rallying. “Such a suspicious critical position,” she notes, “is not necessarily wrong, but it is incomplete” (p. 3); what it lacks is sensitivity to its own limits as one among many different readings of a text.

I provided other examples of singularizing hermeneutics in the previous chapter, regarding how young adults are typically represented within oncological discourses. Generalized images of the ‘distinctness’ of young adult cancer often conceal much of the plurality of illness narratives. Of special importance to my dissertation is the homogenization of biographical and existential challenges, rooted in a singular hermeneutics of young adult development. Though bringing some light to our understanding, these discourses deflect our attentions from their

⁶ In this paper, Croce disparaged Bill T. Jones, a theatre director with AIDS, for using images of dying people in his work *Still/Here* to cultivate in his audiences vicarious despair of loved ones lost to the disease (cited in Jureric, 2012, p. 12-13).

founding ideologies, such as assumptions that narrative coherence and self-authorship are hallmarkers of ‘normal’ young adulthood.

Critical Phenomenology: A Buffer against ‘Hermeneutic Civil War?’

The multifaceted narratives of those going through hard times deserve our attention and respect (Good, 1994; Whyte, 1995; Jureric, 2012). In opposition to a “singularizing hermeneutics” in which scholars must choose to be either complicit or vilified, Odo Marquard (1981/1989) advocated a “pluralizing hermeneutics” in which multiple readings could be posited without their difference leading to violence (p. 123). In the area of illness studies, it seems important to maintain a gentle discordance of representations and a neutralizing appreciation for plurality. Such was a guiding principle in my preceding criticisms of the young adult oncology literature, in response to the singularizing ways in which the lives and illnesses of young adults are often depicted.

A singular critical theory or phenomenological theory is antithetical to seeing illness narratives afresh, in new and illuminating ways, opening up a broader understanding of what life is like during illness. Byron Good (1994) affirmed a “multiplicity of tongues” speaking about illness experiences because “disease and human suffering cannot be comprehended from a single perspective” (p. 62). Contradictory orientations are of comparable merit because they bring something insightful into conversations; different aspects of illness are emphasized and through explication of these aspects something is learned about people’s experiences more generally.

In the spirit of a pluralizing hermeneutics, I used the theoretical perspective of “critical phenomenology,” Good’s answer to the crisis of illness representation and the dangers of dogmatic interpretation (p. 61). Its promise is in possibly answering the question, “How can we write about illness in a manner that heightens our understanding of the realities of lived

experience and still speaks to the larger social and historical processes of which the actors are only dimly aware?” (Good, p. 62).

Critical phenomenology is, at its heart, a dialogical and dialectical perspective. It is dialogical in its process of what cultural psychologist Richard Shweder (1991) called “thinking through others” (p. 108-110). Not just a matter of setting aside my perspective in order to *arrive* at another’s, thinking through others *transforms* both perspectives: a participant’s through revealing what is hidden in their narrative (i.e., distanciation) and my own through coming to question my own hidden assumptions (i.e., appropriation). In sum, this practice is “an act of criticism and liberation, as well as of discovery” (Shweder, p. 110). The critical component has to do with revealing cultural and political forces operating on meanings, while discovery means finding how meanings are personalized and negotiated within individuals’ stories.

The dialectic is between a willingness to suspect and a willingness to listen, what Paul Ricoeur (1976) later referred to as processes of “distanciation” or keeping a critical “estrangement” from a narrative, and “appropriation” or incorporating its meanings within one’s own understanding (p. 43). Interpretation is an effort to “suppress” as well as “preserve” the text’s “estrangement,” to place it in a new proximity relative to ourselves (Ricoeur, p. 43). Critical and interpretive analyses vary in terms of how close or how far they place narratives, but between them is a wide range of placements. From a critical phenomenological approach, these scattered readings may be complementary and may productively inform one another; the structures of lived experiences (as told in stories) may be better understood in relation to the structures of power (such as dominant discourses) that shape experiences. In my case, it was my willingness to listen to the richness of meanings in young adults’ stories that I came to suspect

dominant representations; on the other hand, this richness only became salient when juxtaposed against the ideologies that conceal it.

I do not mean to say that critical phenomenology ‘resolves’ the conflicts of interpretation; it is not necessarily a synthetic perspective going over and above its constituents. Rather, the approach enacts a conversation between the tensions encountered within the research process, between competing ways of thinking, invoking the crisis of representation anew. A reading-with-the-grain is engaged with a reading-against-the-grain, in hopes of enriching discussion and negotiating readings of illness narratives. As a result of maintaining dialogue across the divide, we may be pressed to temper our truth claims, see both the strengths and limits of any one given perspective, and finally, in Jureric’s words, “conceive of a critical practice that adds to our lived experience rather than stands apart from it” (p. 16).

My understanding of critical phenomenology is informed by philosophical assumptions about the interpretive nature of truth and reality, as well as a narrative methodology for studying how personal truths and realities of illness are thematized, structured, and performed in stories. I now turn to each of these linkages in sequence.

Epistemological and Ontological Assumptions

The crisis of representation shows that there are many different ways of thinking about human life; underlying these schools of thought are divergent epistemological and ontological assumptions. Epistemology pertains to what counts as knowledge and how knowledge is attained (Crotty, 1998, p. 8). My research study was informed by an epistemology known as social constructionism, a position of doubt about the objectivity of knowledge, attending instead to its subjective and intersubjective productions through people’s interactions with each other and their

local worlds (Crotty, p. 9). Thus, it may be said that there are multiple, varying truths dependent upon historical and cultural context (Crotty, p. 45-48).

Whatever insights I offer into the lives and concerns of young adults with cancer is subject to several social negotiations, for instance: between myself and those I interviewed; patients' families and caregivers; those who have also studied young adult cancer; my participation in surrounding cultural discourses; and so on. These ongoing social negotiations, according to hermeneutic philosopher Hans-Georg Gadamer (1960/1989), preclude one true or complete meaning that can put an end to all interpretation (p. 427)—something like an objective knowledge. Nevertheless, when we acknowledge our interpretive anchoring within these negotiations, we reveal to ourselves and to others our epistemological vantage points, that is, where we stand within the complex arenas of social locations and theoretical frames.

Both critical and phenomenological traditions share social constructionist understandings of knowledge, though obviously with different foci. Among critical perceptions of knowledge, negotiations may be seen to take place within “hegemonic” relations of rivaling interests, biases, and sources of power (Crotty, p. 60-63). Knowledge may be seen more as a competition of ideologies than a pursuit of higher enlightenment, its attainment like a treaty between two warring states where, as the idiom goes, ‘history is written by the victors.’ Within phenomenological approaches, knowledge may be seen as more cooperative productions, co-constructed by “peaceable” dialogues, shared interests and mutual (attempts at) understanding (Crotty, 1998, p. 60-63). Befitting a critical phenomenology, my analyses explore both these varying relationships within illness narratives.

Ontology pertains to the nature of existence and of reality (Crotty, p. 10). The ontology I held throughout my research study was a form of weak realism, assuming that there may be real

objects out in the world and any form of consciousness may experience them, but the way they are and the way they appear may differ from person to person, or from situation to situation. What is real is not readily obvious and may, in fact, be contingent upon how one is socialized to perceive the world. Blended with constructionism, weak realism upholds the existence of multiple realities out of which different meanings may be produced. As an ontology for critical phenomenology, a weak realist position assumes there are many realities expressed in narratives. In the encounters between narrators' and audiences' realities may be potential frictions and barriers, though within these interactive spaces new realities may be constructed.

The crisis of representation is a lingering preoccupation in my study of illness narratives. Above, I disclosed the influence of critical and interpretive approaches on my theoretical perspective, and how critical phenomenology enables a dialogue between them. From here on I draw perspective into practice, the methodological processes of carrying out a critical phenomenology of young adult cancer.

Methodology and Research Process

Introduction

I proposed in chapter 2 that narrative analysis can be informative for revealing the diversity of young adults' lived experiences and their engagements with dominant discourses. Critical phenomenology does not depend upon a narrative analysis, but the two seem to go hand in hand rather well. Narratives are a subspecies of representations studied by interpretive and critical approaches. Through the study of narratives it is possible to gain a fleeting glimpse of the subjects of interest to a critical phenomenology: the nature of illness experiences as well as the larger social forces and discourses influencing how illness is experienced and understood.

The second half of this chapter entails: a) the research process facilitating the production of narratives, b) a description of the forms of narrative analysis I employed for my dissertation, and finally, c) some descriptive details regarding the sample of young adults I interviewed. My conclusion marks the end of these last three introductory chapters and the beginning of my analyses of young adult cancer narratives.

A) Research Procedures

My dissertation research came out of a larger project conducted by Drs. Ulrich Teucher (my supervisor) and Roberta Woodgate (co-investigator), concerning how young adults make sense of life with cancer. I came into the project with my own research questions, theoretical framework, and methodological approach, all integrated into the interview protocol. The project was funded by the Social Sciences and Humanities Research Council and had received ethical approval from the University of Saskatchewan Research Ethics Board prior to being carried out (Appendix B). With this funding as well as the funding of the Qualitative Research Centre (QRC), we had the resources to recruit young adults from across Canada to talk about their experiences with cancer. My role within the larger project was manifold as I spearheaded recruitment, data collection, transcription, and analysis.

We used a number of recruitment strategies for the project. For Saskatchewan residents we handed out pamphlets and letters of invitations (designed by Dr. Teucher and some members of the CYA research team, see Appendices C and D) to the Saskatchewan Cancer Agency, HOPE Cancer Help Centre, and other related clinics or support organizations. Certain interest groups (e.g., Young Adult Cancer Canada, Gilda's Club, etc.) broadcasted these invitations online; I also designed and distributed a Facebook page through word of mouth (it has since been

shut down in accordance with the REB Ethics agreement). Over the course of about 9 months (from November 2011 to July 2012) I recruited and interviewed a total of 21 young adults.

We collected narratives in two different ways. In our consent form (see Appendix E), sent to people in advance of their agreeing to participate, we outlined that people had the choice between three options: writing a short account of their cancer experiences, participating in a research interview, or doing both. Regardless of which narratives participants agreed to provide, we supplied them with a \$20 iTunes gift card for their time and help. The purpose for gathering written as well as oral narratives fed into some of the interests of the larger project on making sense of young adult life with cancer. In particular, we were interested in how people construct their stories differentially in contexts of writing versus contexts of telling.

Writing a personal narrative can in some ways be dissimilar to talking with another in an interview. For example, the dynamic between narrators and audiences can be quite different. Ricoeur (1976) observed that a written narrative is often “addressed to an unknown reader” not readily apparent, while the audiences to spoken narratives are often ‘live,’ there in the moment of its telling, and thus the story is “addressed to *you*” (p. 31). In other words, intended audiences are narrowed and personalized in speaking, possibly tailoring stories to those present. Furthermore, in person extra contextual information or “demonstration” (Ricoeur, 1976, p. 34) is provided through non-verbal gestures, intonation, and subtle interactions; on the other hand, written narratives often try to help readers imagine being there through metaphors, allusions, genres, and other literary forms (Ricoeur, 1976, p. 34-37). Thus, in their own ways writing and telling employ narrative forms to shape their meanings and provide understanding.

With these and other considerations in mind, multiple stories of illness from the same person may appear quite different according to whether they are written or spoken. Comparative

analysis between written and oral narratives is not a primary research question within this dissertation. Still, the issue informs some of my analyses and reflections in the following chapters, as it is a matter of narrative structure (i.e., how the story is told) and performance (i.e., when, where, and to whom is the story told). Having more than one narrative for most participants demanded deliberation on the contexts around their production.

While the written narratives were given little instruction outside of asking young adults to speak about cancer and its impact on their lives, the interviews were semi-structured through a loosely employed protocol (see Appendix F). They typically involved three parts: first, an introduction to the study and some demographic questions (e.g., age, occupation, ethnic background, etc.); second, a broad question about what young adulthood was like for participants prior to being diagnosed; and third, a much longer conversation about what it was like to have cancer, with some supplementary questions. While the primary questions were general in nature, inviting people to select what stood out as most relevant, I would sometimes ask more specific questions about people's senses of their bodies, attentions, feelings, relations, expectations and activities before and after having cancer.

Before beginning the interview I explained that the purpose of this research was to study the lives and challenges of young adults living with cancer. We usually agreed that more research is needed on young adult cancer, and I said that my main contribution would be exploring what is at stake for the people I interviewed. I made few promises to them, outside of publishing and presenting my findings in settings that would likely have health researchers, care providers, and/or other cancer patients as their audiences (e.g., the Canadian Association of Psychosocial Oncology conference, the *Qualitative Health Research* journal, etc.). I did not promise to seek out their feedback on my analyses, only to contact them if I needed further

clarification on something they said (which happened on a few occasions). I invited questions at the end of the interviews and offered my contact information in case concerns emerged later on.

Two-thirds of the participants did both activities, while seven people declined to write for personal reasons: some were too busy, uncomfortable with writing, did not know what to write, felt they had ‘said it all’ in the interview, etc. The written stories I received were comparably rich in detail but much, much shorter in length than the interview transcripts, and as a result my analyses are disproportionately rooted in the latter. The written stories were used most often to ‘fill out’ a complex representation of their lived experiences, providing complementary material to the interviews.

The interviews ranged in length from just over an hour to nearly three hours, with the average being approximately an hour and forty minutes. Roughly half were conducted in person; for Saskatchewan residents they were set in either the QRC or a negotiated meeting place and for some Ontario residents I was able to afford travel to their locations for a brief period of time. The other interviews were conducted through telephone conversations. All interviews were audio-recorded and transcribed by myself or another research assistant.

I established a set strategy for transcribing the interviews with the research assistants. The interviews were transcribed nearly verbatim, but some nuances and signs were inevitably lost because “transcription is not reduplication, but metamorphosis” of the data (Ricoeur, 1976, p. 42). All silent pauses were recorded, but not length of time. Not every filled pause was recorded (e.g., uh and um) as we tried to juggle capturing the subtleties of speaking with maintaining the readability and flow of the transcripts. For the same reason we did not transcribe intonation or emotional expression (i.e., as sometimes done by adjusting text size or font). Because of my interest in the teller-listener relationship, relatively more emphasis was placed on transcribing

my verbal confirmations (e.g., mmmm, okay, right, yes) and non-linguistic vocal gestures with possible relational significance (e.g., laughs, coughs, sighs, throat clearings, etc.). I proofread and edited the transcripts written by others to ensure a relatively consistent ‘metamorphosis’ of the spoken interviews into written text.

B) Methodology: Narrative Analysis

Different aspects gain more attention than others within varying traditions of narrative analysis, from the study of universal structures of speech in sociolinguistics to the context-specific use of genres and grammar in literary theory, to the interpretive anthropology of stories as expressions of self and culture (see e.g., Mattingly, 1998, p. 11-15; Riessman, 2008, p. 76-78). Divergent methodologies come out of divergent interests; however, they may be and are sometimes brought into dialogue, combining “in bricoleur-like fashion ideas and methods from here and there as these have been deemed useful in analyzing [stories]” (Mattingly, 1998, p. 11).

I took advantage of the procedural freedom of narrative analysis and brought together three analytic techniques as described by medical sociologist Catherine Riessman (2008): thematic, structural, and performative analysis. The first, *thematic* technique was used to answer the question, “what is told?” (Riessman, p. 105). Thematic narrative analysis is parallel to other qualitative methodologies, such as phenomenological analysis or grounded theory, in building a substantive interpretation of lived experiences; however, it stands out from other methods in that it “keep[s] a story ‘intact’”(Riessman, p. 53). Narrative analysis often entails reconstruction of the evolution of themes across a plot; in my project, I looked at the emplotment of meaning and being while living with cancer. I chose thematic analysis because it enabled me to catalogue the diversity of stakes involved in the young adults’ stories, a few among which were attempts to make sense of what happened, position oneself within the story’s events, communicate the

unknown to a naïve audience, explore possible pasts and futures, and resist dominant expectations about recovery.

Included in the content of a story is its context, namely, the “relationship between the individual life story and the particular society” (Personal Narratives Group, 1989, p. 10-11). This is where analysis goes beyond simply reporting what is at stake in individual narratives to consider how those stakes weave into discursive constructions of young adulthood and life with cancer. I carried out comparative analyses across narratives for the sake of observing variations on a theme, accounting for nuances and differing developments in how meaning and being are negotiated (Riessman, 2008, p. 74). Each chapter includes demonstrative exemplars and studies how their dominant themes unfolded similarly and differentially.

A second technique, *structural* analysis, can have many different meanings, but they typically centre on the question, “how is a story told?” (Riessman, 2008, p. 105). By studying narrative form, we can start to understand “how participants use speech to construct themselves and their histories” (Riesmann, p. 103). Furthermore, structural analysis may involve evaluation of “cultural and social patterns” of thinking, wherein we “suspend, or make problematic, common-sense thought and generally held beliefs of everyday life” (Rothe, 2000, p. 150). From my perspective, structural analysis is inherently built into narrative analysis. Keeping a story intact means taking into account formal characteristics of emplotment, most notably temporality (i.e., when something happened and how it relates to what happened before and after it). Therefore, structural analysis was a necessary approach to interpreting how the participants’ storied their stakes, and how their choices of emplotment shaped their expressions of meaning and being.

In the way just described above, what is told and how it is told are possibly inseparable, but they do require a different lens to observe their effects on a story's meanings. Unlike thematic analysis, structural analysis takes issue with the process of narrative construction, including "literary and cultural models which help shape people's life stories, the social and historical conditions affecting their life experiences, and the family relations in which the life develops" (Personal Narratives Group, 1989, p. 10). By comparing individual stories to the narrative environments within which they are told, we can see how the former may utilize and resist common forms for communicating to others. The following chapter takes on the most extensive use of structural analysis in order to set up the dominant genres of my participants' narratives, but throughout this dissertation I combined structural with thematic analyses.

Performance analysis was my third strategy, adding to the overall analysis by asking the questions: when and why was a story told, and to whom is it directed? (Riessman, p. 105). In other words, for what "use" is a narrative constructed and how am I, as a reader, to respond to it (Personal Narratives Group, p. 11). Performance analysis involves a "close reading of contexts, including the influence of investigator, setting, and social circumstances on the production and interpretation of narrative" (Riessman, 2008, p. 105). In keeping with the method, within which "intersubjectivity and reflexivity come to the fore" (Riesmann, p. 137), I used performance analysis to reflect on the teller-listener relationship, the actions involved (i.e., the 'act' of constructing narratives, as well as the 'act' of listening and responding to them), and their ethical and political implications. The whole dissertation is interspersed with performance analysis, but chapter 6 is heavily dependent upon the method in its consideration of audiences and applications of moralized cancer narratives.

Treating narratives as performative acts requires an important disclaimer about my conclusions. As already noted in chapter 1, I worked with *expressive* meanings, those constructed in narratives and so limited in their applicability beyond the situation of their production. In addition, performances require actors and audiences, and through their dialogue meaning is constructed (Good, 1994, p. 142-144; Ricoeur, 1984, p.70-71). I am therefore implicated in others' expressive meanings. Though I set out to understand the local worlds of young adults during times of illness, the following chapters contain syntheses of my participants' performances and my interpretive participation as an audience. A hermeneutical task through and through, creating images of cancer in young adulthood is an activity of co-construction between those involved in discourse. In recognition of this activity, I add in my concluding chapter some reflections on my participation and response to the meanings produced in the narratives.

I drew the three analytic angles of thematic, structural, and performative analysis into an iterative process of interpretation, a "close reading" of each narrative with attention to subtleties, contexts, and transformations of a narrative's elements (Charon, 2006, p. 113). From the page of a transcript to a page in the following chapters was a long, meandering journey through several points of interest. First, I conducted a series of readings for each person's narrative. In my initial reading I meticulously decorated the margins of the transcript with any thoughts, commentary, reflections, criticisms, superficial thematic categories, and other notes I thought relevant to my project. I carried out a second reading in search of answers to the question, "what is at stake in this narrative?" I asked this question meticulously at every turn of the page, listing the aspects of self and experience that seemed to be emphasized in the texts and tied them to perceivable needs (e.g., a sense of continuity, belonging, life direction, etc.). At this point I was not selective in my

analyses; I would often switch from thematic to performative to structural analysis depending on what seemed most relevant and informative to me at a particular time in my reading.

At the next step in my journey I started to compartmentalize my analyses. I initially focused upon structural analysis, re-plotting storied lives into temporal sequences within which to place significant events and themes. Specifically, for each transcript I divided a page into columns and transferred information from the transcript into either the time before cancer, the time of first symptoms and diagnosis, the time of treatment, the time of post-treatment, or the time of the present. This helped me to see the earlier lives from which each person entered the drama of cancer, as well as where he or she had ended up at the time of the interview.

After this reconstructed emplotment, I studied the significant themes expressed within and across each sequence, which revealed the stakes within each narrative sequence and how they evolved over time due to changing circumstances and desires. At this point in time in my interpretation, I started to develop what would become the major foci of my analytic chapters. Moral explorations first emerged as a dominant concern across the narratives, especially attempts to link present suffering with past events and to pursue an ethical future after experiencing suffering; these two stakes led me to into what would eventually become chapter 6.

Though morality was the first theme, it moved into the later parts of my analysis as it gradually appeared to be a derivative of more fundamental concerns for placing cancer experiences within stories of action (i.e., narrative forms) and locating oneself within these stories (i.e., narrative identities). Initially, I had a fourth category of stakes related to intersubjective negotiations, but eventually subsumed that under the theme of narrative identities as it became apparent these negotiations were almost always about where to place the young

adults within their stories (e.g., as agents responsible for the causes/resolutions of their suffering or as patients who should submit their bodies to the experts in charge of healing).

As these three themes became more salient within the narratives, I decided to enter into a targeted literature review on each one. While my chapter 2 review of psychosocial oncology and narrative identity development served to develop a rationale for my research project, I felt I had not adequately explored the issues that had become the most important findings within my research. Thus, I read up on some important literature on narrative forms, identities, and moralities (the results of which, eventually, became the introductions to chapters 4-6). I placed these readings within concept maps, which provided a theoretical context through which I further interpreted the narrative themes. Throughout the analytic chapters I incorporate these additional concepts into my theoretical framework (see Figures H1, I1, and J1).

These targeted reviews served another purpose: assessing the dominance of discourses. While I was in writing my proposal, I was in search of dominant discourses in psychosocial oncology; at that time, I defined dominant discourses as uncritically engaged representations of young adult cancer within certain institutions (e.g., CIHR, CCS), cancer support organizations, and published academic research⁷. I saw them as relatively more *sedimented* than other discourses into larger social spaces of experience. Battle tropes, for instance, exemplify a narrative form that has spread its sphere of influence across many different contexts, not just cancer experiences but medicine in general and, to go further, much of everyday social life. I centred my proposal upon the sedimentation of narrative coherence and self-authorship within representations of cancer and young adulthood.

⁷ The assumption here is that the most dominant images are those that are often taken-for-granted, invisible to suspicion, and in their repetition have developed a power to influence others.

I continued these assessments of dominance in my targeted literature reviews. I compared my earlier conclusions about psychosocial oncology with the said selective bodies of research, as well as with participants' commentaries on (both in support of and against) what they saw as prescriptive language about cancer experiences. As a result, I interpreted the presence of the imperatives of narrative coherence and self-authorship within discourses about genres (i.e., narrative form=narrative coherence), identities (i.e., agency and consummated being=self-authorship), and moralities (i.e., moral explanation=narrative coherence, personal responsibility=self-authorship). These equations were not just observed within the literature; they were typically emphasized, encouraged, and presented without juxtaposition or contradictory evidence. It is against these predominant assumptions about cancer and young adulthood that some of my more critical analyses are directed, but not without accounting for some of their merits and uses.

Still within thematic analysis, I colour-coded the stakes of formalization, identity formation, and moralization within each of the rendered narratives. Encountering repetition in the stories and comparing these codes with the above bodies of literature, I started to develop a working list of categorized themes and then made a table for sorting out how each person expressed these themes. Thus, over time, I built up a range of narrative genres (e.g., journeys, battles, mysteries, etc.), identities (e.g., patients, tricksters, advocates, etc.), and moral explanations (e.g., psychological, biomedical, etc.) from the dialogue between interviewees' narratives and the reviewed literature on illness narratives.

In order to balance my more critical and more interpretive perspectives, I entered into performative analysis just before the writing process. Specifically, I asked what was being accomplished in their narratives in relation to the research context; more to the point, why or

why not was narrative coherence and self-authorship not salient within a particular moment in time. The issue of critical witnessing, in chapter 6, arose from this more reflexive analysis, as an attempt to articulate and manage some of the expectations and dynamics that are brought into the relationship of teller and listener.

The last step within this interpretive journey (though I returned to earlier points again and again) was writing up the analyses as an engagement between idiosyncrasies within individual stories, dominant narrative themes across participants, and relevant theoretical concepts within the research literature. I typically weaved conceptual discussions into evidence within the narratives, but I changed the way I narrated my dissertation according to my purpose. When writing about broadly observed results I analyzed a number of different metaphors used across the young adults' stories, which may be understood as short-hand "kernels" of emplotment—or, moments of meaning in my conceptual language—that inform the whole of the longer narratives (Teucher, 2003). When writing about the idiosyncrasy of certain narratives, I analyzed a select few exemplars over the course of their particular plots.

I hope in these varying interpretive practices to have demonstrated shared aspects of narrative forms, identities, and moralities while accentuating the diversity and creativity of each person's story. I often use visual representations within this manuscript as interpretive aids, condensing the girth of information that I felt was necessary to my task. As mentioned above, I also use visuals to reintroduce my theoretical framework within each of the next three chapters, adding new concepts to it (signified by italics and underlining) as they relate to the issue at hand.

C) Participants' Characteristics

While some research may seek homogeneity within a sample (in order to 'control' for extraneous 'factors'), critical phenomenological research comes at a topic with an interest in

multiplicity, with the intention of revealing peoples' manifold selves and meanings. I have provided a table of some participant characteristics to show the diverse demographics of the sample (see Figure G1 in Appendix G).

There were, of course, common patterns and characteristics to the sample. Among the 21 people who participated in this study, nearly all were middle-income, European or Caucasian Canadians; the only other ethnic background reported was Asian Canadian. The majority of people came from two provinces: Saskatchewan and Ontario. Most of the people I recruited in my home province were from word of mouth through friends and associates, but a couple came from advertisements I had issued. Ontario was heavily represented because it contains one-third of the country's population. On top of that, compared to most other provinces, it has a rich network of organizations engaging in advocacy and support work for young adults: Gilda's Club, Wellspring, Maplesoft, and many others offer programs specific to young adult survivors. When I asked them to pass along information about my study, word of mouth again spread across in-person and online connections. Young Adult Cancer Canada helped me tremendously, reaching contacts in places throughout the country I would have otherwise never found.

There seemed to be good distribution of participants across age and gender. People in their late twenties to early forties were very well represented in this group. Looking to gender, despite the disproportionate number of women, this is a relatively balanced representation. Far fewer men participate in psycho-oncological research than women, with some studies reporting as low as 15-30% representation of men (e.g., Decker et al., 2006; Zebrack, 2008). Notably, most research on young adults with cancer do not even report how many men and women they studied (e.g., Grinyer, 2007; McGoldrick et al., 2011; Riley et al., 2011).

There are important contexts around the construction of their stories needing mention. Many of the participants had written the stories before, usually for more public consumption: blogs, newspapers, online profiles, etc. None of them wrote professionally, although twelve had had post-secondary training and were thus somewhat familiar with writing—one had even started his narrative in the style of an essay defining and explicating terms from neurology and oncology. A few had training in pedagogy and had some experience teaching others.

In terms of exchanging stories with other patients, outside of larger city centres there was very little person-to-person contact with other young adults, in support groups or patient-matching programs. While the web enabled young adults to communicate with each other from across the country, these interactions were neither as frequent nor enduring as they were for people involved in support groups. In addition, some of the similar themes of people's narratives is also partially an artifact of snowball sampling, where the people who agree to join are likely to know and appropriate the stories of others who have already participated. A significant consideration for analysis, for people in continual contact with one another may shape each other's narratives, forming discourses that may not be shared by those outside of their 'circle.'

The details of people's cancers were also quite diverse (see Figure G2 in Appendix G). Nine different types of cancer were accounted for in this study. They represented a mixture of epithelial cancers (i.e., carcinomas of the breast, cervix, colon, etc.) and non-epithelial cancers (i.e., leukemias, brain gliomas, Hodgkin's and Non-Hodgkin's lymphomas, etc.). In line with research on gender and young adult cancer, more women had epithelial cancers than non-epithelial (8 vs. 5), while the reverse was true of men (2 vs. 6).

As can be seen, participants' cancers were in a wide spectrum of stages. There are many ways to stage cancers (e.g., the Tumour, Node, Metastasis [TNM] guide), but most people's

healthcare teams seemed to use the Overall Stage Grouping, from Stage 0-4. Stage 0, or carcinoma *in situ*, is when cancerous cells have not invaded surrounding tissue. Stage 1 has invaded local areas of the body and may be surgically removed, while in Stage 2 the cancer has often advanced enough to require chemotherapy and/or radiation as well. Stage 3 is a further localized progression of cancer, while Stage 4 marks metastasis into other areas of the body.

Getting information on the stages of people's cancers was surprisingly difficult. Just over half knew with confidence the stage at which they were diagnosed, with the other half not entirely sure. There are two major reasons for such a high number of unknown stages. Four participants said that their diagnoses vacillated depending on who they talked to in their healthcare team, and thus weren't clear on the severity of their illness: in three cases, the diagnosis ranged from Stage 1 to 3, while the fourth ranged from 2 to 4. The remaining five could not remember if or what they were told at the time of diagnosis.

We may interpret the ambiguity of staging in a variety of ways: perhaps the participants were not that concerned about their stage; perhaps staging was overshadowed by the word "cancer" and not heard; perhaps there are difficulties within oncology in staging young adult cancer accurately; perhaps caregivers were evasive about sharing specific details; and so on. Each explanation was applicable to some extent within the young adults' stories.

Much more than staging, the majority of young adults were quite concerned with how long they had had cancer. The amount of attention given to time since diagnosis may have something to do with three-quarters of the sample having cancer for less than 5 years. Most survival ratio statistics are assessed at the 3-year or 5-year mark and can become for many a 'finish line' beyond which they consider themselves to have 'survived' cancer. A lot of weight was placed upon these statistics, and in turn a lot of anxiety during follow-up appointments

within that time frame⁸. Indeed, those who were beyond 5 years since diagnosis seemed notably less interested in the number of years passed. All this despite the enduring prospect of relapses at any time; the three participants who did have a relapse were at one, three, and seven years post-diagnosis. This is often how the statistics are used, as a deceptive measure of certainty for an unpredictable disease and future (Jain, 2007).

Chapter Conclusion: Proceeding to Analyses

Here we are at a transition, from the study's introductory chapters on theory and method to its substantial analyses of the narratives. There is much more to be said of the participants' characteristics, and more broadly about the study's characteristics, but these details come into relevant discussions in the following chapters. The remaining pages explore the moments of meaning and being expressed within participants' narratives of cancer: from considerations of narrative forms in chapter 4, to analyses of narrative identities in chapter 5, to a discussion of moral meanings in chapter 6, up to a concluding chapter 7 on this study's major findings and implications. Throughout the moments of meaning and being brought into this dissertation are conversations between critical and interpretive ways of understanding young adult life with cancer.

⁸ One woman who was told she had a high survival prospect with just surgery still underwent five years of tamoxifen to increase her chances by an estimated 1%: "1 percent is 1 person out of a 100 like that, that's one person who will die if they don't do chemo so give me the chemo."

Illness Narrative Genres

Her name is Yoshimi
She's a black belt in karate
Working for the city
She has to discipline her body
'Cause she knows that
It's demanding
To defeat those evil machines
I know she can beat them.

—The Flaming Lips, *Yoshimi battles the pink robots*

Introduction

In 2002, the psychedelic rock band The Flaming Lips released an album called *Yoshimi battles the pink robots*. The album tells a story of a young woman dying of breast cancer from the perspective of a compassionate male witness, perhaps a caring boyfriend or brother. In order to make sense of her illness and to maintain hope for her survival, he sees the young woman as a freedom fighter, reinventing her as a Japanese warrior who possesses an unflinching courage. He imagines they are in an apocalyptic world being invaded by an army of conniving, destructive machines. That world will be lost unless somebody resists their advances, and the man positions his beloved as the hero, trained in martial arts and ready to ward off total annihilation.

However fantastical the imagery, mythic stories like the one above powerfully express the gravity of the pain and struggle experienced by a dying cancer patient and her closest intimates. The unnamed storyteller in the Flaming Lips album does this by use of particular narrative forms, in this case through a war story. The scene of the hospital bed is transformed into a battleground, while visiting friends and families appear as helpless bystanders watching the forces of good and evil fight to determine the fate of their world. Battle stories have arguably

become a *trope du jour* or “prototypical plot” (Good, 1994, p. 146), a dominant genre for today’s cancer stories (Hunsaker-Hawkins, 1993, p. 88); as a case in point, the commercial success of the Flaming Lips album precipitated its adaptation into a rock opera. Stories with dominant war themes are among other genres that are “so familiar to the public that the public uses them as keys” (Todorov, 1968/1981, p. 62); however, they hang upon a hefty key ring of other ready-to-hand narrative forms.

My purpose in this chapter is to study some of the keys jingling in the young adults’ pockets, for they open doors to constructing meaning and being in complex ways. My attentions are temporarily narrowed on moments of meaning; the different genres discussed below set the stage for analyzing moments of being in the next chapter. The analyses within this chapter are divided into three sections, corresponding to three important generic considerations: *narrative forms*, *narrative contexts*, and *narrative purposes* (Personal Narratives Group, 1989, p. 100-102). These explorations inform the critical task of my study in showing use of prototypical plots along the axis of narrative coherence; that is, I evaluate the extent to which young adults used these narrative forms to integrate their experiences into orderly representations of cancer.

The first section builds upon exemplary and foundational scholarly work on illness narrative forms (e.g., Couser, 1997; Hunsaker-Hawkins, 1993; Frank, 1995; Rimmon-Kenan, 2002; Teucher, 2001a, 2001b) by cataloguing a range of “prototypical plots” within the interviews. As part of a “pluralizing hermeneutics” (Marquard, 1981/1989), I exhibit the multiplicity of narrative forms within and across the young adults’ stories, which vary according to their construction of narrative coherence.

The second section entails a modest interpretive pursuit of some cultural contexts, namely, relevant narrative environments that may have contributed to the narrative forms of the

young adults' stories. Among many different muses I could discuss, I chose those deemed to be quite influential in the lives of today's young adults, including the stories of popular fictional media and dominant genres in medical and public rhetoric about illness. Then, I weigh the dominant plots in fictional and non-fictional discourses against the hierarchy of plots seen within my study, finding some different trends in this comparison.

The uses and purposes of narrative genres make up the third and final segment of this chapter. Included are three exemplary narratives that show the creative application and utility of different genres. I consider possible reasons these three young adults evoked some narrative forms over others, and the many different needs that may be (and may not be) expressed by them. What we come to see is that narrative coherence is but one of many stakes involved in structuring narratives of illness. I draw the chapter to a close by affirming that stories of illness must be situated within the forms, contexts, and purposes of their making in order to recognize and appropriate these many possible stakes. .

A Note on 'Genres': Sedimentations and Innovations of Meaning

It is difficult to define the term 'genre,' though in its many definitions it is used to discuss works of art according to style or form. Structural literary theorist Tzvetan Todorov (1968/1981) referred to genre as the "signifying organization of 'discourse'" (p. 16), a way of structuring texts into particular arrangements. Tied to this function of genres are the shorthand "kernels" of meaning known as metaphors (Teucher, 2003). These techniques carve out the shapes and meanings of a narrative. They may be identified by asking, "how does a text signify?" (Todorov, p. 16).

Beyond Todorov's relatively abstract definition, genre is an elusive and problematic term. Thomas Couser (2005), a literary scholar of disability life writing, wrote that it is often

unclear what is a genre, sub-genre, or sub-sub-genre because people do not agree on the hierarchical organization of generic categories (p. 140). Within literary theory, for instance, Marlene Kadar (1992) wrote of “life writing” as an umbrella term subsuming autobiography while her colleagues Sidonie Smith and Julia Watson (2001/2010) placed them on equal footing as different sub-genres of life narrative¹.

Some have rejected use of the term as too structuralist, placing complex and diverse narratives into “tidy categories” following rigid “rules” (Personal Narratives Group, 1989, p. 99). In response, some scholars refer instead to “narrative forms” (Personal Narratives Group, p. 99) or “narrative types” (Frank, 1995, p. 75-77). I heed the above advice about the simplifying dangers that plague discussion of genres; however, the term does not need to be understood in an obstinate way and, indeed, literary discourses about genres have shifted in recent decades to recognize flexibility in form. Couser (2005) claimed “notions that genres are pure, stable, rule-bound, and distinct compel little credence today” and contemporary scholars tend to see genres “as plastic, fluid, and perhaps inherently hybrid entities that may emerge, evolve, and eventually die out” (p. 141). Contemporary notions of genre enable recognition of narratives that modify, play around with, and refuse to follow formal ‘rules.’

That does not mean we disregard the traditions upon which illness narratives today are inspired. According to Paul Ricoeur (1984), “a tradition is constituted by the interplay of *innovation* and *sedimentation*” (p. 68; my emphasis); that is, in a variety of ways individual narratives both deviate from and reproduce customary forms of storying life. With regard to the latter, meanings are sedimented through the establishment of formal rules, norms, or codes for

¹ Free usage of the prefix “sub-” to talk of genres adds no clarity to the issue, and I confess I may also be inconsistent in this regard. Let me try to manage some of the confusion by stating that the plots I spend most of the chapter on are technically sub-genres of illness narratives, which are themselves sub-genres of life writing. That said, below I demonstrate the ‘leakiness’ of this neat hierarchy.

constructing a text (Derrida, 1980/2000, p. 220-221; Ricoeur, 1984, p. 31-33; Todorov, 1968/1981, p. 18). The “rules of the genre” may provide narrators with a “model of writing” while shaping finite “horizons of expectation”² among audiences (Todorov, p. 62). Among the many ‘sedimented’ meanings within illness narratives are “prototypical plots” (Good, 1994), available storylines for narrating illness in socially familiar ways. Prototypical plots thus become “cultural possibilities and models” for telling and hearing narratives (Personal Narratives Group, 1989, p. 100).

Even stories that strive to resist these customs, like feminist critiques of male-dominated forms of narratives, may rely upon preceding standards of intelligibility (Personal Narratives Group, 1989); the fissures they forcibly create may only be seen against the sedimentary backdrop of normativity they puncture³. In a sense, then, stories are constructed in response to what is socially deemed to be “appropriate and familiar,” even if the response is primarily critical (Personal Narratives Group, p. 100). Yet, such disruptions to tradition may transform it, and rules may be challenged, modified, and contested. This is often an ideological affair, as traditional rules tend to conceal marginalized or non-dominant narrative forms (Personal Narratives Group, p. 6-8).

² His use of this phrase is not accidental to my use of it. Both Todorov and Ricoeur (who I draw upon) take it from German literary theorist and philosopher Hans Robert Jauss.

³ I should note that though Derrida, Ricoeur, and Todorov shared a normative notion of genre, Derrida (2000) seemed to disagree that all stories must work within the rules of the genre in order to subvert it. Instead, he envisioned resistance narratives that “mark a collapse that is unthinkable, irrepresentable, unsuitable within a linear order of succession, within a spatial or temporal sequentiality, within an objectifiable topology or chronology” (p. 223). At the time he was writing about the bounds of intelligibility, an issue I find, by necessity, quite difficult to traverse let alone find an end to it. The debate is whether at the tip of the intelligible world we are sucked into a maelstrom of meaninglessness or inevitably pushed back into it by the shore-bound waves of dominant narratives. This issue amounts to a disagreement between post-structuralist and structuralist visions of narrative order; I try to address this tension delicately throughout the remaining chapters, though at the risk of oversimplifying my position I will briefly state that both and neither fates are possible: sometimes our stories are pulled out into the infinity of the inexpressible, sometimes they are held fast by readily available meanings, and perhaps most often they hang somewhere in between, floating toward and away from cultural spaces of experience.

Some patients refuse to tell the types of stories that are indoctrinated into their social worlds because they do not account for the many potential disruptions people may experience while living with illness (Frank, 2010; Rimmon-Kenan, 2002). Herein lies the innovative side of narrative construction, the negotiative power individuals have access to in interpreting their experiences. People may transform larger myths about life with illness into more locally resonant worlds of meaning. Different prototypical plots may be used loosely and in combination with others (Good, 1994, p. 146; Neuman, 1992, p. 223-226; Whitehead, 2006). For instance, the abstract criteria for distinguishing a coming of age narrative from a young adult cancer narrative may seem exclusive and rigid, but the “actual genres” embodied in individuals’ stories may “admit, on the contrary, diversity and coexistence” (Todorov, 1968/1981, p. 19). New plots may be created through the dialogue between available forms, the contexts of narration, and individual purposes for telling their stories (Personal Narratives Group, p. 102).

Thus, there is a singularity to each story, where no two narratives are the same (Charon, 2008, p. 45-47). As Arthur Frank (1995) stated, “people tell their own unique stories, but they compose these stories by adapting and combining narrative types that cultures make available” (p. 75). Some have argued that this marks a “post-modern” period for illness narratives (Egan, 1999, p. 14; Frank, 1995, p. 4; Morris, 1998, p. 3), involving a “hodgepodge” of storylines that “[contain] multitudes” (Egan, 1999, p. 15-19). It may, therefore, be appropriate to think about genre in a microscopic way, as pertaining to bits or sequences of stories, as modestly marked *moments of meaning* instead of homogenizing labels. Figure H1 (in Appendix H) demonstrates how this position on narrative forms fits into my overall interpretive toolset.

Illness Narrative Forms: Moments of Meaning in Stories of Illness

Prototypical Plots in Young Adult Cancer Narratives

If misunderstood generic analysis could be taken as an exercise in pigeonholing, which is not at all my intention. My task is precisely to study the creative blending of generic categories in the framing and forming of young adult cancer narratives, for the purpose of relating them to the expectations of narrative coherence in dominant discourses. Talk of genres should serve not a categorizing but a “clarificatory” function, as “comprehension of [generic] hybridity depends on naming and identifying the various sub-genres in play” (Couser, 2005, p. 144-145; see also Thomas-Maclean, 2004). We must appreciate the originality and specificity of each narrative, but not at the expense of knowing the historical and cultural circumstances that shaped them. Below I discuss an array of prototypical plots and dominant metaphors employed in innovative ways, expressed as moments of: a) fighting, b) sojourning, c) healing, d) inspecting, and e) disordering⁴. See Figure H2 for a visual representation of the moments of meaning and their different motifs (numbered according to prevalence).

A) Moments of Fighting: Battles, Politics and Athletics

As mentioned in the introduction, stories of fighting are among the most familiar prototypical plots within cancer discourses. There were many sequences in the young adults’ narratives when cancer experiences were emplotted as moments of fighting, though they were talked about in different ways. I found moments of fighting to be most often set as battles against cancer, political struggles with others, and athletic struggles to overcome personal limitations.

Like the man who imagines Yoshimi defending her land and taking down menacing intruders, many people thought of some aspects of their cancer experiences as a kind of *battle*. Stories of battle are pervasive in public discourses, where cancer is externalized as an ‘other,’ a

⁴ The quoted texts within this section come directly from the participants’ narratives.

foreign adversarial body that is battling it out with patients' cellular defences (Sontag, 1978, p. 66-67; Teucher, 2001b, p. 166). Patients' bodies become warzones and the stakes are ownership of the territories (Hunsaker-Hawkins, 1993, p. 66). Just over half of all the young adults I interviewed utilized this prototypical plot of illness at some point in their narratives, often in reference simply to "fighting" or "battling" cancer.

Often their stories described the course of events as follows: discovery of a lurking enemy (diagnosis), mobilization of resources (determining the best treatment), a defensive attack ("cut, poison, and burn", as crudely put by some⁵), and a survey (biopsies and blood tests) of the strength of either side. Across these plots and metaphors of military procedure, the young adults talked about using "aggressive" treatments on their cancer, being "in the trenches," seeking the "strength" and "bravery" to carry on, motivated to "win" the war on their disease, and determined to "conquer" the "world" that is in danger of being destroyed. They talked of treatment as an "arsenal" or "secret weapon" designed to "destroy" or "kill" cancer cells, and a few people visualized their cancer "dying" during their chemotherapy or radiation treatments. When treatments were unsuccessful, particularly for other cancer patients, they talked about "losing" or "lost" battles.

In some circumstances, like that of the imagined Yoshimi, the connotation of foreignness took a radical form as an alien invasion, invoking a science-fiction plot (Sontag, 1978, p. 66-67) like that of *War of the Worlds*. Living with colorectal cancer in her thirties, Laura described her disease as a "monster":

C: And what sort of features does this monster have?

⁵ For instance, Counseling psychologist Brenda Hunter (2004) wrote critically of surgery, chemotherapy, and radiation as "barbaric" for inflicting such violence on patients' bodies. However, her "new ally," Dr. Linda Seligman, encouraged her to "combat [cancer] on all fronts," defined by her as the body, mind, and spirit (p. 8-9).

L: He's, he's big. He's black. He's scary. He's got teeth and he's probably got a gun, and he's willing to take anybody down, you know?

C: Mhm, it's very powerful, very (J: Yeah), very dark. (J: Yeah) Um, what else stands out for you for this, this monster?

L: The fact that he's just ruthless, the fact that he doesn't value life. (C: Mhm) (Pause). The fact that he's calculating, 'cause he, he probably lurks and y-you know, goes where the weakest part of your body is so he'll attack there and hold on, you know?

Here as elsewhere in young adults' narratives, cancer was seen as a vicious and conscious villain, deliberate in its actions and corrupt in its motives. Cancer was sometimes referred to as simply "evil," and Laura along with another woman, Penny, specifically described their battles in religious language, seeing themselves as "God-chosen" warriors engaged in a divine war. When they interpreted their battles on grander scales, as threats to humanity, they emphasized the importance of "rallied" support, a collective effort and "interlocking hands" of "allies," in order to overcome cancer.

Sometimes allies were not so cooperative and the language of battle shifted to interpersonal conflict. Alliances sometimes broke down and disagreements ensued over how to proceed. At their worst, an ally—usually a care provider—started to be seen as an enemy of, or at least interference to, the best interests of the patient. During these hard times, war efforts were redirected toward, for example, oncologists who the young adults identified as stubborn or negligent (Hunsaker-Hawkins, 1993, p. 66-67). Battles often became *less militaristic* and *more political* in such circumstances; patients employed techniques of rhetoric in order to gain support, and this sometimes led to heated debates with their caregivers.

A large minority of my interviewees noted alliance breakdowns at some point during their care. In these moments of meaning, the young adults saw "*advocacy*" as the primary fight within their care, doing their "own research" into symptoms and treatments (e.g., "Googling" it),

“taking responsibility” for their own recovery, “challenging the assumptions” of their care providers and striving to be heard. They talked about feeling “rushed” by “forceful” oncologists, “disputing” with doctors who “don’t listen” to their concerns, and seeing their time in healthcare as a “struggle to be taken seriously.” For example, 34-year-old Lorena, who had lung cancer, was “angry at the fact that [the oncologists] weren’t willing to try radiation and they weren’t willing to operate on me, even though I would have gladly volunteered...I definitely wish that, like, my doctors had been in my corner.”

Miscommunication and disagreement were not limited to patient-doctor relationships. Other alliances were said to be at risk as well, most notably the support of patients’ families. Some described their spouses or parents as “useless,” “fractured,” a “mess,” clueless of how to understand or care for a loved one with cancer. Family tensions sometimes became battles unto themselves, as when 31-year-old Jeanine who suffered a “bombardment” of questions about cervical cancer from a family insensitive to her needs and concerns, or when a “turf war” developed between the wife and the mother of 39-year-old George while he was recovering from leukemia treatments. As with caregiver disagreements, the young adults struggled for a voice, wanting to advocate for themselves among a familial arena of competing interests and needs.

Some battles were more oriented toward self-refinement than overcoming or negotiating interpersonal strife; they often emplotted struggles as *athletic* obstacles (Hunsaker-Hawkins, 1993, p. 76-77). Rather than a fight to the death, the conflict was—mind the pun—within oneself, between one’s limitations and endurance. Much less common than battle stories but slightly more frequent than stories of advocacy, athletic plots constructed cancer as a “hurdle,” “challenge,” or “marathon,” one involving “training” and preparation, as well as the strength to “confront fears” and “never give up.” Some spoke of needing a personal “coach” or a

motivational figure, usually a family member, caregiver, or celebrity athlete with cancer (e.g., Lance Armstrong).

Post-treatment time was often perceived as the “finish line,” when patients were “triumphant” and had “overcome” their cancers, showing “gratitude” for all those who helped them along the way. One woman who took up exercise classes post-treatment, Beth, wrote about becoming mentally and physically “stronger” than she’d ever been and more than she’d ever expected of herself. The sense of conquering ‘internal’ obstacles was for her a sign of hope and inspiration toward a future without breast cancer. Lorena’s statement about wishing her healthcare team was in her “corner” (as in boxing matches) pulls from this athletic language as well.

Moments of meaning related to ‘fighting’ may be positioned in a variety of ways, some of which include militaristic, political, or athletic conflict. Other battles may also be seen in cancer narratives, likened to struggling with one’s faith or resisting evil, facing social conflict or ‘societal decay,’ and taking control of nature by ‘battling with the elements’ (Teucher, 2001b, p. 168-169). These different battles can signify a variety of issues at stake in living with cancer, including conquering over evil or injustice, establishing one’s own voice, transcending one’s limitations, and many others.

In the context of youth, some war imagery may also draw upon dominant Western discourses of adolescence and young adulthood, as a time of “storm and stress” within oneself (for some history on the use of this phrase, see Arnett, 1999). For example, a few participants spoke of young adulthood as a “fight” to build a successful career, “wrestling” to find love and to be “ahead of the game.” Cancer in young adulthood may be seen in these moments of meaning as yet another battle within (or shortly after) already turbulent times.

Though battle stories may be most familiar among the different narrative genres used in cancer narratives, as I have shown there is a great deal of diversity within them. Let us now turn to the multiplicity beyond them, in other prototypical plots of illness, starting with the genres of journey narratives.

B) Moments of Sojourning: Journeys, Banishments, and Near-death Experiences

Moments of sojourning relate to prototypical plots that typically involve a sense of travel and adventure. A variety of sojourns may be present in illness narratives, which require patients to exit everyday life and enter a “new world” rife with foreign customs, bizarre values, and exotic dangers (Hunsaker-Hawkins, 1993; Frank, 1995). I discuss three particularly notable motifs within this context: journeys, banishments, and near-death experiences. These stories speak of a deprived sense of home: friends or families may seem worlds away as their loved ones traverse the geographies of their emotions; spiritual explorations may take them into hitherto unimagined places of divine or dark inspiration; and so on.

However sojourning may be imagined, illness tends to be constructed as a pursuit toward edification (e.g., Mosack, Abbott, Singer, Weeks, and Rohena, 2005). Cancer is still seen as a source of much anguish, but it holds out an opportunity to ‘gain perspective’ on one’s life (Frank, 1995, p. 115). In comparison to moments of fighting, moments of sojourning employ less adversarial language, and tend to carry a “less aggressive, quieter, and more introverted ethos” (Hunsaker-Hawkins, p. 78).

A wide range of sojourning plots may emerge in illness narratives. *Journeys* are perhaps the most general of such plots. About three-quarters of my participants referred to their illness as a “journey,” “adventure,” or “quest,” sometimes more specifically as a “rollercoaster” or a “ride,” along a “windy” or “bumpy” or “blocked” road, going “downhill” into a “valley,” or

going through several “phases.” Having cancer had set in motion a “new life” or “new path,” one that left them forever “changed.” The dominant theme expressed in these moments of meaning was movement along an unpredictable but hopefully finite and rewarding quest.

Most of the young adults’ narratives envisioned treatment as a journey “ahead,” a “plan of action” offering “direction” and “going somewhere.” Sometimes their “tour” of the healthcare system was seen as a “minor detour,” beyond which they would be on the “other side” of the “cancer world,” “continuing on the same path.” One of the most common journey emplotments used was around hopes that treatment and post-treatment adjustment would enable them to “move on” from their suffering, get “back on track,” or see some “movement” in their situations. These moments of meaning alluded to possible expectations among young adults that cancer will be a temporary interruption to their lives, as suggested by Kathy Charmaz (1992). When these expectations were disappointed, people felt they had fallen “behind,” were caught in journeys that were “never complete” or “never over.” They spoke of “searching” for some sense of home, “routine,” or “normality” again, “needing guidance” for how to live on after cancer.

Catherine, who at the time of the interview was still receiving chemotherapy for colon cancer, said, “There’s nothing worse than being 30 years old and unable to care for yourself. Umm, coming out of surgery was the same, it’s, yeah it’s tough and it’s a struggle and it’s slogging through crap.” This journey was still very present for her, and she said it was often hard to see an end in sight. She said that through the course of her treatments she gradually came to see that “life is not gonna be what it was” and faced a difficult question: “What am I supposed to take from this? There has to be a lesson, this can’t just be for nothing.” Catherine’s words resound with many of the young adults’ narratives, expressing frustration over not appearing to learn a ‘lesson’ from cancer.

She also pointed to some of the “mental tourism” that other young adults encountered, where they explored the landscapes of their perceptions and assumptions, seeing a hopeful perspective as among the most salient journeys during illness (Hunsaker-Hawkins, 1993, p. 78). The young adults sometimes talked about seeking to find a “gift” or “lesson” within their experiences. They were usually cautious to add disclaimers about cancer being an unwelcome gift or mixed blessing, but it still had an edifying element, whether a “new outlook,” some “understanding” about life, or personal “change” for the better.

In her mid-thirties with cervical cancer, Penny blended two seemingly incompatible personifications of cancer: an entity of “evil,” as we saw in the previous section, and a “teacher” taking patients upon an educational journey toward seeing the world in new ways. She titled a part of her written story “What cancer has taught me”:

It teaches you to love deeper than you ever did before because you may not have a tomorrow. Cancer teaches you to find the good in any situation. Cancer strengthens the bonds of true friendships. Cancer makes you find the words when you thought there weren't any left. It teaches you to appreciate the simple pleasures of life like a bird singing in a tree or the smile on your child's face when they hand you a handful of dandelions. It teaches you to evaluate your priorities. It teaches you to work through your emotions and decide if you should smile, cry or scream.

This list goes on for a couple of pages, showing the wide extents of cancer’s ‘influence.’ Despite her hostility toward her disease, she repeated most other young adults’ claims to being taught “love,” “appreciation,” and “empathy” for others, and to “reevaluate” their lifestyles. Cancer illuminated some beloved part of their worlds that had been previously neglected. Teachers can, of course, have varying personalities; they can be mean, even misanthropic as Penny saw hers, and they can educate people on things they didn’t want to know about, like bloody discharges, invasive surgeries, survivor’s guilt, and other undesirable illuminations. This was often the case among the young adults. A young woman in her thirties, Martha, summed up her mixed feelings

toward her teacher in this way: “I freaking hate that I had cancer – but I love the person it made me.”

Sometimes young adults would be accompanied by “guides” and “fellow travelers” (e.g., care providers, loved ones, or other cancer patients), but much more often their journeys were done “alone.” With a more intense degree of alienation and separation, and yearning for a world that has been lost, these moments of meaning expressed plots of “exile” or *banishment* (Hunsaker-Hawkins, 1993, p. 79). Over half of participants described being “uprooted,” “shipped off,” sent along a “conveyer belt” to “another world” away from their own. They constructed their new worlds as unappealing places, like a “dark tunnel,” “desert,” “island,” or “boat in the ocean.” Across these different metaphors is a theme of having no choice in the journey one is on, of being sent against one’s will upon a saddening and perilous trip without company. When describing their cancer journeys this way, participants talked about being “set back” from what they saw as the normal course of life, feeling “isolated,” “confined,” or “lost,” not where they “expected to be” and “going nowhere.”

Expressions of banishment were often used in reference to long periods of waiting for answers or for recovery. Dismissing her caregivers’ cautions about infection as paranoia and feeling impatient for the end of her journey, Catherine went shopping during chemotherapy treatments and caught a flu over which she had to be admitted to emergency. She said, “After that I was kinda scared to go out anywhere, so I really didn’t for the next like, like next 6 months.” Though not detained against her will, Catherine had to distance herself from a social world consisting of malls, clubs, and other public places. Stories of banishment put emphasis on distressing experiences of alienation and “unhomelike” being (Svenaesus, 2000), aspects of illness that signify unwilling segregation from others. In a sense they are seized journeys, for the

young adults were stripped of the freedom of movement and exploration during their time ‘away’ from others. Weighed down by fatigue and nausea, some people simply laid in bed, hoping to be released one day soon back into their communities.

A smaller minority of young adults (about a quarter) told of travels to yet another world: the realm of the dead (Hunsaker-Hawkins, 1993, p. 80). Journeys telling of *near-death experiences* were mentioned within several narratives of more advanced cancers (i.e., Stage 3 to 4), but they were most prevalent among the few brain cancer patients, who not only had some of the worst prognoses but also whose treatments had stopped before having removed all visible cancer cells⁶. Those who saw their journeys heading toward the land of the dead spoke of having “almost died,” believing they were at “the end of the road” and that it was “game over.” They “prepared” for their seemingly final journeys by writing their wills, receiving the sacraments, planning their funerals, or “living like [they were] dying” (e.g., spending money hastily, dispensing with a vision of the future, etc.).

With glioma in a very sensitive area of his brain, Adrian’s doctors were not sure the treatment would really improve his situation...so they left it. They forewarned him that there was little hope for a future: “My oncologist even told me to not be so focused on a degree but just the act of going to university when so many doctors have their doubts.” In Adrian’s and the others’ cases, the omens of death within a year or two did not occur as predestined. Here is where survival statistics can be most misleading and most distressing for cancer patients (see e.g., Jain, 2007), though, to be fair, in this study we are exposed only to the narratives of those who lived, and many have not come back from the dead to speak about terminal medical predictions that were accurate. Having an indeterminate time of life left, these young adults told of a time ‘after’

⁶ Across the board, the primary reason cited for the cessation of treatments was that care providers believed the treatments would likely kill their patients before the cancers would.

being near death; a “new side opened up” at the end of the road, revealing a “new start” or a return “back to what you would call normal.” With their prognoses still looming over head, they were also in a limbo of sorts, a period of “waiting” to see where they would end up and when.

Moments of sojourning all seemed to emplot life with cancer as a time away from home. Outside of that dominant theme, the young adults told of a variety of journeys, from reflective explorations of thought, to banishments to unfamiliar worlds, to liminal experiences of being in-between life and death. This wide range of use demonstrates the flexibility of this genre, as some young adults told of journeys that had an identifiable end to them—a return ‘home’ after a time of being ‘unhomelike’—while others left the end more open-ended, not yet in sight. Cancer is rarely just one journey, rather like many mini-journeys initiated and completed at various times throughout the narratives.

C) Moments of Healing: Medical, Transformative, and Serendipitous Recoveries

Many of the above moments of sojourning articulate some form of ‘return’ to a sense of homelike being. Stories involving “restitution” (Frank, 1995) or “redemption” (McAdams, 2006) also refer to restored health, order, or equilibrium in life. However, what are particular to Frank’s (1995) restitution narratives are their moments of healing in particular: “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (p. 77). These recovery plots often begin with the onset of symptoms, searches to locate and “fix” the root of the problem, and implementation of the cure (Frank, 1995, p. 88-89; Rimmon-Kenan, 2002). It may seem tautological to talk about recovery in illness narratives that don’t end with patients’ deaths; however, what narrative moments of healing signify can go well beyond what we might think of as wellness in contexts of chronic illness.

People can conceptualize recovery in a variety of ways; dominant within the young adult stories were three different but sometimes co-occurring ways of coming into healing: through medical intervention, spiritual transformation, or serendipitous circumstances. By some appearances they may be perceived as quite contradictory; indeed, some of the characteristics Arthur Frank (1995) lent to recovery narratives—like patient passivity to the ‘expert healers’ (p. 91-92)—were not essential to them, as we shall see below, and were also seen in moments of sojourning where patients talked of being banished or forced into their travels.

Arthur Frank discussed at length stories of *medical recovery*. In such stories a “mechanistic view” of the body often dominates, constructing healing as a process of fixing and tuning up broken, fleshy machines (Frank, 1995, p. 84-88). People submit their bodies to the “cure-promising authority” of modern medicine (Rimmon-Kenan, 2002, p. 22) as a passive vessel of regimented treatments (Frank, 1995, p. 86-88). Personal responsibility in such narratives is limited to taking one’s medication and letting care providers do their work; thus, restitution narratives are sometimes seen as less of a personal story of illness and more of a testimony to the expertise of others (p. 91-92).

These forms of recovery connote *retroversion*, that is, returning to a prior state in contrast to coming into a new space of understanding. Contra journey metaphors of cancer as a “gift,” “lesson,” or “discovery,” recoveries often express (desired) restoration of the way things were, a mode of being unencumbered by the burdens of illness. This way of thinking about cancer reflects more “interruptive” experiences and expectations of illness, wherein cancer may be constructed as a temporary crisis, a brief episode with a “predictable outcome: recovery” (Charmaz, 1992, p. 13). Within the field of oncology, both spaces of experiences and horizons of expectation are shaped by these prototypical plots of momentary illness.

The majority of young adults expressed recognizable moments of medical healing. Responsibility was placed primarily upon care providers; people said that they had “trusted” their treatments, had “faith in surgeons and chemotherapy,” and “expected to get better.” For their part, they “followed the plan” and “just [laid] in bed.” In post-treatment time, they saw themselves as “normal again,” “not changed” by the experience, “alive and healthy,” “fixed,” “cured,” and confident their medical team “removed” or “took it all.” They said they were “relieved” and “thankful,” with “low anxiety” about the effectiveness of their medical care.

There were sequences in the young adult narratives when they internalized some of the responsibilities of their recovery, minimizing the roles of contingency and medical care. A different curative discourse emerged in these moments, suggesting people must take a more active role in their care and conceiving of disease and treatment in spiritual or psychosomatic terms (Hunsaker-Hawkins, 1993, p. 3-4, p. 28-29; Mount, 1993, p. 52; Ignatieff, 1988, p. 28-29). Two basic assumptions are built into these narratives, noted by Susan Sontag (1978): the “primacy of ‘spirit’ [or mind] over matter” (p. 54) and, by extension, healing of the spirit/mind as a prerequisite to bodily recovery (p. 45-46). These different prototypical plots have thematic connections to religious conversion narratives, where healing is marked not by the preservation of old ways but by personal *transformation* (Hunsaker-Hawkins, p. 31-37).

Transformative recovery plots were only marginally less common than medical recoveries, meaning that a sense of individual responsibility for illness was expressed frequently among the young adults. Most often the narratives took on the form of psychosomatic healing. People implied that the course of their illness was partially determined by their emotions and thoughts; they believed they “must be positive” and “break out of negativity” (e.g., thinking about death, dwelling upon loss and suffering, expressing anger about misfortunes, etc.), they

must “protect against stress” which can be a “killer,” by evoking “humour” in their situation, seeking advice on “self-help,” acquiring a “sense of control,” and “visualizing” their bodies getting better. Other aspects of their “lifestyles” were also considered pertinent, like “diet” and “exercise.” By changing their minds and actions, they expected their bodies to follow.

Personal responsibility was also expressed, to a lesser degree, in terms of spiritual connection or purification. Some individuals spoke about the need to “accept” and to “rejoice in suffering,” for in it is “post-traumatic growth,” positive “change” in who they are, and so on. A few of these plots emerged from a Christian language of “redemption,” stressing the importance of “prayer” and faith in God. Instead of retroversion, as in medical recoveries, emphasis is placed on *conversion*, the ways in which having a serious illness can enhance spiritual or religious sensitivities.

A smaller cluster of plots seemed to interpret illness as *serendipitous*. In these moments, the young adults did not bestow responsibility upon any particular agent of healing beyond chance and contingency. We see allusions to serendipity when the young adults talked about being “lucky,” “fortunate,” or “blessed,” a “rare” or “ideal” case where their cancers were by “fluke” caught in early stages, they “responded well” to treatments, and/or had few lasting complications. They applied these metaphors to what they saw as exceptional and fortuitous circumstances of their illness and recovery: chance discoveries of tumours, very responsive caregivers, supportive families, financial coverage or security, etc. Within these narratives and metaphors, the young adults appeared to be more considerate of the different social contexts within which people live through their diseases, seeing recovery as more dependent upon being at the right place and time than being under the scopes of modern medicine or being personally in charge of healing.

For instance, Lee received a mammogram in her forties for a lump she found on her breast. This turned out to be a stroke of luck she says: “The lump that I had found was benign [but] it’s only because [G.P.] did take me seriously and sent me for the mammogram that we found the micro-calcifications, which were in fact malignant.” This second lump turned out to be Stage 0 breast cancer. She saw a series of fortunate events leading to this discovery and treatment of her cancer: she found the lump only days before her doctor’s appointment; her physician responded to a perceivably innocuous lump with a mammogram; her first screening mammogram for breast cancer would have been years later, at age 50; and, caught so early, she only needed surgical treatment. Lee suggested that without the role of serendipity, she may have had a more severe diagnosis years later and may have not survived it.

It may be hard to see the diverse moments of healing above as under one roof—in some ways they are worlds apart—but they share one dominant theme. Recovery stories often address matters of etiology and curative power, for it is assumed that to know the treatment one must identify the cause: for biological disorders, biomedical interventions are necessary; diseases of the soul require spiritual transformation; and unlucky plights are undone by changes in fortune. Not to say such explanatory models are not present in other prototypical plots, but their prevalence stands out in recovery narratives. We will revisit and expand these issues of etiology and personal responsibility in ch.7 in relation to moralizations of cancer.

D) Moments of Inspecting: Mysterious Symptoms, Criminal Plots, and Infiltrated Borders

I observed another series of moments of meaning, based upon prototypical plots that are quite pervasive but relatively understudied within illness narrative research (for an exception, see Teucher, 2001b). These plots all expressed moments of inspecting enigmatic circumstances and bizarre occurrences, thereby engaging narrative genres of mysteries. I observed three dominant

kinds of ‘inspections’ in the narratives: making sense of mysterious symptoms, suspecting criminal activity, and discovering infiltrated borders between victims and assailants. Some aspects of past, present, or future appeared uncertain, and the mystery plots unfolded through pursuit, attainment, and doubt of answers.

By far the most commonly told mysteries were around reading *mysterious symptoms* in hopes of pinpointing a diagnosis. Nearly all the young adults noted that they were having “vague symptoms,” with “random,” “puzzling,” and “weird” things going on with their bodies (e.g., bleeding, fatigue, lumps). The “confusion” typically didn’t stop when they sought medical attention; their symptoms were often “dismissed” as medically insignificant or “misdiagnosed” as “depression,” “stress,” or “anxiety.”

Those physicians who took the symptoms seriously still struggled to make sense of them. Some tests came back “inconclusive,” providing “no answers,” “no explanations,” and “no information.” The young adults’ illnesses “eluded” their physicians, prompting one neurologist to tell Adrian, the brain cancer patient who wasn’t sure he would live to graduate from university, that he wished he had “a crystal ball.” Diagnosis often evoked a cautious sense of relief among people who had been searching for answers for months or years, but they did not always protect against mystery. On surveillance, Adrian had serial MRIs to determine whether his brain tumour had inflamed enough to warrant risky radiation treatments; over the course of many years the MRIs showed “no change” or “indication” in the tumour, yet his neuromotor symptoms continued to worsen. For others, there was a flow of inconsistent information coming through to them. In the section on participants’ characteristics in chapter 2, I observed that just over half of the participants knew the staging of their diagnoses with certainty, and one major reason was conflicting reports given by different members of their healthcare teams. Beyond

treatment, the future remained “uncertain” for many young adults, a “mystery” only partially (and somewhat misleadingly) answered by prognostic statistics.

The second most moment of inspecting involved *criminal plots*, which are similar to battles and wars in the sense that cancer is often othered, constructed as a villain or threat to the protagonist’s life. These antagonists often took the form of thieves, tricksters, or murderers. Struggles with these adversaries were usually battles of wit or evasion, working to deceive or escape the other. Like the plots of so many crime mysteries, political thrillers, and slasher films, these diagnostic mysteries contained “elements of innocence, first suspicion, the shock of detection of a deadly threat, historical and medical research, pursuit, and arrest” (Teucher, 2001b, p. 165).

Some young adults said they believed they were being “robbed,” feeling “afraid,” “scared” or “terrified” for their lives, or “paranoid” that it was “all in [their] head.” They talked about how cancer snuck into their lives when they were stressed, overworked, or exhausted; others were more surprised to acquire cancer when they felt they were relatively healthy, eating nutritious foods, exercising on a regular basis, and so on. Their diseases were constructed as opportunistic, catching unsuspecting people during inconspicuous times. The enduring metaphor was that cancer took them by surprise, when their attentions were elsewhere.

Often comments about ‘paranoia’ came with frustration with care providers; in particular, the young adults said they were often “not believed,” they had to “fight to be heard,” their concerns—first about their symptoms, later about recurrence or side effects of treatment—were considered a “non-issue,” and a few were referred to a psychologist for voicing their suspicions. Losing faith in “narrow-minded” doctors and “sloppy” medical work, and aware that their actions were “time sensitive” and “against the clock,” they “looked into it” on their own,

conducting their own private investigations through Google searches, local contacts, other opinions, and support organizations. In sum, they had to ‘play the system’ in order to have their ‘case’ heard.

Attempts to ‘other’ cancer seldom failed, but when this happened guilty parties were identified much closer to home than an opportunistic stranger (e.g., Teucher, 2001b, p. 165). In these moments of meaning, people described suspicion and panic around possibly *infiltrated borders*. For example, some people’s bodies appeared untrustworthy, possibly co-conspiring with the disease; they were, in a sense, double agents. A gray mist arose around the borders between person and disease, victim and assailant. Participants’ bodies were sometimes referred to as “strangers” or as friends who had “betrayed” them. For example, Mandy narrated a love-hate relationship with her body after being diagnosed with Hodgkin’s lymphoma. She says:

It’s tough because, I mean, I mean evil comes to my head. But then that word gets kind of mixed up, because it’s part of you. Right? (C: Right.). It’s your own cells; it’s your own body that’s turned against you. For me, I think I had a hard time separating it and making it, you know, something that wasn’t part of me. Right? (C: Mhm). You know, like if you get, if you get the flu virus, you know, you’ve been invaded by, you know, it’s a foreign invader. But cancer’s not a foreign invader. It’s your body killing itself. So...I don’t know how to describe it.

Mandy seemed to struggle to identify an adversary she could place in opposition to her; friend and foe were not easily discernible. She wanted to cherish her body and appreciate its delicacy, but she also distrusted, “loathed,” and “hated” it. She wanted to put it at a distance, “put [it] on the bed and leave it there” but she couldn’t “escape” or “get out of it.” When we came to talking about her current pregnancy, she said that as much as she “started to love” her body again, she could not be certain it wouldn’t “fail” her again, resurrecting cancer when she and her child would be most vulnerable. Many young adults felt a lingering suspicion that the borders between body and disease were still infiltrated post-treatment and could not ever be fully fortified.

Sometimes the infiltration went beyond the body to include the self. Cancers were suspected to have links to conflicting desires that had become so opposed that the divisive self was enacting its own destruction. A remarkably psychoanalytic angle on mysteries, explanations centred around unconscious motives (especially the death drive⁷), repressed desires, and self-deceit. A few young adults believed they had partially or indirectly contributed to their cancer by repressing “emotional turmoil,” putting too much “stress” upon themselves or leading what they later interpreted to be “unhealthy” lives. These stories carry a residue of mid-twentieth century theories that people with cancer have certain personality traits and lifestyles that foster the growth of cancers (Sontag, 1978, p. 50-56).

Mysteries mark an important genre for understanding illness in a population that is not typically believed to get cancer. Young adults and their doctors alike do not always look for cancer initially, let alone believe it when they see it. Mysteries tend to signify experiences that challenge our notions of predictability and assumptions of foresight: Different readings of mysterious symptoms are contested in clinical settings; suspicions of foul play lead to anxieties and self-doubts; and previously held categories like self and body, or friend and foe, start to leak into one another as patients start to question who they can trust. The moments of inspecting found within my research show tensions within the young adults’ narratives between wanting to understand and fearing what one may find.

E) Moments of Disorder: Chaotic Narratives

The above plots express certain narrative forms of illness experiences, putting disruptive experiences into some sort of order. However, there were many moments within the narratives where form broke down, where life was disordered, and meanings were subverted. Typically, these *chaotic* moments of disordering in narratives are understood as a different *kind of story*

⁷ See *Beyond the pleasure principle* (Freud, 1920/2011).

altogether, distinct from journeys, battles, and so on. For Arthur Frank (1995), chaotic narratives are the “opposite of restitution” and show “life never getting better” (p. 97). While all other genres seem to espouse a sense of control or order over one’s fate, chaotic narratives are seen to express “life’s fundamental contingency” (Frank, 1995, p. 102). Such narratives may articulate what Charmaz (1992) understood as “immersive” forms of illness (p. 73-74), distinct from “interruptive” episodes as suffering is chronically (or terminally) experienced and with exponential intensity. Many others have used Frank’s formulation to inform their own work on disruptive illness (e.g., Mosack et al., 2005; Whitehead, 2006).

A less structuralist approach may see chaotic narratives differently; not as distant, craterous kinds of stories but as everyday aporias of meaning, or plot holes, that many stories have (see e.g., Ricoeur, 1984, p. 73; Thomas-Maclean, 2004)⁸. Sociologist Matt Hyvarinen and colleagues (2010) argued that chaotic elements are among the “necessary and integral aspects of a narrativity that tries to capture an uncharted aspect of experientiality” (p. 9). According to some literary theorists, chaotic and liminal experiences of being outside order may, in fact, be the rule rather than the exception during life with illness (e.g., Gough, 2005; Rimmon-Kenan, 2002); though some narratives may be more ‘orderly’ than others, moments of meaning also bear the “potential of its absence, negation, or irrelevance” (Engelke and Tomlinson, 2006). To categorize them as separate may conceal the presence of chaotic language across illness narratives. Though they were minority moments, all the young adults’ narratives had at least some lapses of coherence, unanswered questions, or enduring mysteries.

Chaotic narratives are perhaps not part of an independent genre, but represent the precariousness of meaning when trying to make sense of illness. As prototypical plots are

⁸ Recall that, in chapter 1, I argued that meaning is indeterminate and narratives are not guaranteed to have a recognizable form or order. Moments of chaos are among several ways in which narrative coherence is disrupted; another way is through subjunctive explorations of meanings (Turner, 1986).

negotiated with lived experiences, we may see some expressions of chaos within the different moments of meaning. For example, moments of fighting may either arrive at a stalemate or cede to the enemy; some participants found their treatments “demoralizing” or “overwhelming,” they felt “vulnerable” to their illnesses, and “refused to engage” out of fear.

Similar disordering may be seen in moments of sojourning. During their adventures people sometimes described feeling “lost” or “purposeless”; their journeys took them to “hell,” or they felt that “life is on hold,” has “shut down,” and they were “not living” but just “laid on the couch” and suffered. Instead of seeking out “lessons” from their experiences, they struggled to “process,” “absorb,” or “remember” what they had been through, or, alternatively, tried to “forget” or “distract” themselves from thinking about it.

Many moments of healing expressed only temporary/partial healing or indefinite deferrals of recovery. They challenged assumptions and expectations of “normality,” and expressed anxiety and doubt about the “effectiveness” of medical treatments as they saw “slow” or “halted” progress. A few people saw themselves as “damaged,” “not whole,” “not healthy,” or “wasting away.”

Finally, some moments of inspecting bled into chaotic stories. A few people said they were “freaked out,” “unsettled” by and “terrified” of the dark unknown. A few others felt there was “nothing more” for their cancers to “take,” so much had their bodies and identities been stripped away already. In thinking about the future, many young adults gave up on concrete images or expectations, concluding that it is all a “mystery,” there are “no final answers,” and the possibility of recurrence was always there.

Moments of disordering may signify the ubiquitous instability of narrative order, prompting literary theorist Shlomith Rimmon-Kenan (2002) to ask to what extent people

“conceal disruption under a semblance of continuity and/or victory” (p. 14). Some narratives may indeed reflect more chaos than others, but it seems more productive to talk about a spectrum instead of a distinct narrative genre. By extension, the imperative of narrative coherence seems to overlook these nuances of meaning, and may even fuel attempts to conceal disruption.

Conclusion: The Multiplicity of Narrative Genres

Young adults’ stories of cancer can be couched in a number of different terms. By no means have I exhausted the vast range within which their stories may be structured; I have only reviewed some dominant genres that seemed to be at work within my participants’ stories, the many battles, journeys, recoveries, mysteries, and chaotic moments that emplot their lived experiences. Most of my participants evoked at least three of these plots, and in some narratives all five may be found. Referring to the genres of individual narratives as moments of meaning helps here, as our language shifts from a dichotomy between narrative order and disorder to co-existing moments of order and disorder, the “discordant concordance” of stories (Ricoeur, 1984, p. 73) that embody people’s struggles to understand life with chronic illness. It may be better to refer to these forms as ‘moments’ within a narrative rather than as different kinds of narratives, noting both the temporary presence of meaning or being at a given point within a narrative as well as its eventual absence or transformation over time.

Seeing such a colourful bouquet of narrative forms should give us pause and a chance to appreciate the diversity of young adults’ stories, the many images and moods they may elicit among their recipients. The next step within the broader purpose of this chapter is to plant this diversity within the pots of history and language, various muses within the young adults’ narrative environments. My analysis ideally helps us to understand where young adults’

emplotments may come from on a broader social and cultural level, the ways in which larger discourses and their generic organization may attract particular moments of meanings.

Illness Narrative Contexts: Influential Narrative Environments

Framing Young Adults' Stories of Illness

Young adults are primed for emplotment, ignited by the many stories they encounter in everyday interactions, books, movies, YouTube, etc. They may use these narratives to interpret and construct their own lives, including particular episodes like illness. I turn to some culturally sedimented meanings within the young adults' narrative environments that may provide at the very least a departure point and at the very most a model for them to tell their stories of illness. I look to some of the cultural forms that seem to be most often consumed and are, presumably, most likely to shape young adults' cancer narratives: a) fictional stories and b) medical and public rhetoric of illness.

The media and discourses available to young adults are vast and exceedingly diverse fields, and their proposed impacts need to be qualified. First of all, I cannot possibly review all or even most possible cultural influences on young adult cancer narratives. The following contextualization is intended as a briefly surveyed, backgrounding frame, not as the focal point of the chapter. Second, notwithstanding the widespread access to the Internet, social media, bookstores, and television, I cannot assume that similar media forms or contents reach the dispersed Canadian populations from which my interviewees came. Third and finally, young adults clearly have divergent preferences from one another and any conclusion about what genres inspire them must heed the limits of generalizing statistics.

A) Contexts of Fictional Stories: Prototypical Plots in Film, Television, and Literature

During his study of social dramas, cultural anthropologist Victor Turner (1981) observed that social conflicts tended to take on similar structures to theatrical performances, especially tragic plays; furthermore, the theatre seemed to imitate current happenings in social life. As a result, Turner concluded a dialogue between everyday life and artistic expressions, where the one inspires the other into being (p. 149). Other scholars in a wide range of disciplines have since defended his claims, arguing that everyday stories are shaped dialogically by fiction and history, myth and mundane experience, imagination and memory (e.g., Bruner, 1990; Freeman, 2010; Hunsaker-Hawkins, 1993; Mattingly, 1994; McAdams, 1993; Ricoeur, 1985, 1988). It is from this argument that I propose fictional narratives are relevant here.

Arguably the most influential medium of fictional storytelling among young adults is not live theatre *per se*, but its contemporary cousins: film and television. In their study of the “worldviews” of today’s young adults, psychologist Sara Savage and colleagues (2006) found their interviewees constantly referring to fictional movies or television shows in storying their own lives (p. 73). Cinematic fiction seemed to provide two services to young adults: a juxtaposing image to compare and contrast with ‘real’ life, and a framework for imagining their ideal worlds and futures.

We may see some parallel plots between generic preferences of fiction among young adults and the moments of meaning employed in their illness narratives. These applications are sometimes easily and readily prepared by movies like *50/50* (2012)—an advertised quasi-autobiography portraying a twentysomething male live through neurofibrosarcoma and the resulting loss of his girlfriend, tensions with his best friend, and the precarious effects of chemotherapy. Most films, however, require a longer stretch and a more metaphoric linkage

between everyday young adult life, including life with chronic illness, and the sorts of grandiose trials common to Hollywood protagonists (think, for a moment, of the action films of Arnold Schwarzenegger).

According to some media research, there are a few common generic tastes that many young adults seem to share. For example, media psychologists Fischhoff, Antonio, and Lewis (1998) noted that the four most favoured prototypical plots of film among young adults (ages 13-25) seem to be action-adventure (a synthesized category of battles and journeys), romances, science fictions, and dramas, respectively⁹. This differed remarkably from middle and older adults, who had much more interest in dramas and less interest in action-adventures. It is also notable that though among one of the least favoured across all ages, murder/crime films were significantly more popular among young adults than older adults. It is possible that the relative favouritism of action, adventure, and crime dramas may partially explain the presence of battles, journeys, and mysteries in the young adult narratives.

Many of the prototypical plots of film have redemptive endings, making restitution a dominant form of *dénouement*. Historians Neil Howe and William Strauss (2000) put this trend into context, observing a shift in popular media toward a “happy business” in the last few decades (p. 239). They claimed that in many strands of modern media, emphasis is placed on either exaggeratedly happy endings or plots mostly devoid of high stakes conflict. Life’s takedowns are deliberately softened and getting back on one’s feet is portrayed as an easier and more total recovery. This is one way in which popular media, like blockbuster films, may encourage (or impose) more coherent narratives among its audiences.

⁹ Unfortunately, the researchers cited above put little effort into defining and reflecting on generic categories, and use expedient labels that do not always capture the complex and genre-crossing plots of many films. Nevertheless, they provide some clues to the kinds of stories that capture young adults’ imaginations.

Literature can have a similarly profound effect to film on how people construct their own life narratives. Historically, battle stories told around illness may build upon many literary myths and celebrated fictions of our culture (Hunsaker-Hawkins, 1993, p. 61), whether it is the ancient Greek mythic war between the Achaeans and the Trojans in *The Iliad*, or the J.R.R. Tolkien fantasies *The Hobbit* and *The Lord of the Rings*. These and many other war myths perpetuate organization of the world into dualities of light and dark, life and death, good and evil, and tell of the unfolding conflict between the two over time (Hunsaker-Hawkins, p. 61-63). Battles against cancer may symbolically invoke mythic stories of struggle against a perceived enemy of peace; imagery of cancer as “evil” and a “monster” are just a couple signs of these mythic influences.

Narratives of transformative recovery have also endured over a long period of Western history and across different forms of life writing. Arthur Frank (1995) noted this historical preservation in his comparison of non-fiction illness and spiritual narratives. Religious conversions bear a more notable mark in earlier times, when the “confessions” and transformations of Saint Augustine, Jean-Jacques Rousseau, and Leo Tolstoy resonated with a collective concern for healing afflictions of the spirit (Frank, p. 32). In contemporary times, more materialist discourses have made the material body (i.e., *Körper*) of primary interest, and so we tend to talk more about bodily illness and medical healing than about soul sickness and transformative recoveries (Couser, 1997, p. 5; Frank, 1999, p. 32). Nevertheless, he concludes, “even if science has tended to replace religion as the official mythology of a secular culture, religious ways of thinking and imagining still persist” (Frank, p. 49). Prototypical plots of soul healing in earlier confessionals seem to permeate many of the recovery stories discussed above, sometimes in explicitly religious languages of prayer, redemption, and rebirth, other times in the

more recent language of psychoneuroimmunology constructing the mind as the locus of cure (see e.g., Mount, 1993).

The world of reading is one less traversed by young adults today than film but is still quite common. According to some recent national research by the Pew Center in America, 83% of young adults had read a book within the last year (Zickuhr, Rainie, Purcell, Madden, and Brenner, 2012). Among the most popular books read by young adults are “mysteries, fantasies, and horror thrillers” (Howe and Strauss, 2006, p. 171), including the works of J.K. Rowling (the *Harry Potter* series), Stephanie Meyer (The *Twilight* series), and the pervasively well-known suspense writer Stephen King. These stories are not to be discounted as irrelevant to cancer experiences, as they often articulate encounters with, for example, unexpected adventures, villainous adversaries, internal conflict, and the fearful unknown. They also often explore issues of being banished from home, having near-death experiences, and living with serendipitous fortunes and misfortunes.

At the heels of these successful fantasy writers has been an emerging interest in young adult fiction that is more directly exploring mental or physical illness. Including main characters suffering from depression, suicide ideation, cancer, cystic fibrosis, or other chronic difficulties, this so-called sub-genre of ‘teen sick-lit’¹⁰ is being sought out by younger readers as much as or sometimes more often than the above mythic stories. One of the most notable examples is John Green’s (2012) *The fault in our stars*, a story of two teenagers with cancer who together try to contend with how to live and die meaningfully. *TIME Magazine* chose *The fault in our stars*, which was advertised as young adult fiction, as the #1 fictional book of 2012. Not to dismiss the verisimilitude of more imaginary forms of fiction, but these stories often have a stronger realist

¹⁰ I am cautious in using this phrase, for it has been criticized for simplifying the complexity of the characters and plots within such stories (see e.g., the January 9, 2013 episode of CBC’s *The Current*).

mood to them, exploring specific health issues that could actually happen to their readers, possibly facilitating reflection and understanding of chronic illness.

It could be argued that film, television, and books are little more than modes of entertainment, and many young adults report them as such (e.g., Mundorf and Brownell, 1990). However, as stories rife with metaphor, symbolism, and allegory, as “virtual experiences of being-in-the-world” (Ricoeur, 1985, p. 100), they may also communicate ways of understanding non-fiction life. Indeed, Fischhoff et al. (1998) make the convincing case that people’s preferences in film and television may relate to their social identity, that is, they value stories within which they can see some part of themselves; the same may also be true with literature. Life and art leave their sticky imprints on each other. Whether it is an Arnold Schwarzenegger film or John Green novel, the fictional worlds created within may bleed their radiant ink onto the young adults who enter into them, becoming part of the skin they wear in their own worlds of existence. The popularity of battle, journey, mystery, and recovery narratives may be reflected in their frequent appearances in the young adults’ narratives of illness.

B) Contexts of Medical and Public Rhetoric: Prototypical Plots in Discourses of Illness

Looking at some cultural discourses outside of fiction and entertainment, let us enter the realms of medical and public discourses regarding illness. By ‘public,’ I mean larger conversations across local communities, as may be seen in national debates, widely broadcasted media, and online forums. These two contexts overlap quite a bit, likely co-constituting each other. Comparing medical and public rhetoric, we see two dominant prototypical plots shining out from their surfaces: battle narratives and recovery narratives.

There is a particularly tight affiliation between the language of war and medical rhetoric. A long historical link can be seen between war and medicine; while surgical procedures were

advanced on the battlefield to treat wounded soldiers, radiation and chemotherapy were first designed for combat. The latter two still carry these connotations in the way medical professionals talk about treatment, often referred to as “weapons” designed to “bombard” the “invasive” bodies that threaten patients’ safety (Hunsaker-Hawkins, 1993, p. 64; Sontag, 1978, p. 63-65). For instance, the very first cobalt therapy unit to use gamma rays for treating cancer—built in Saskatchewan in 1949—was nicknamed the “Cobalt Bomb.”

Along with metaphors of military power are symbols of purifying power. Modern medicine is said to be driven by a “telos of cure,” an overarching project to rid the world of all ailments (Frank, 1995, p. 83). Medical discourses tend to encourage recovery narratives by promising medical knowledge is up to the task of any puzzling illness. Seeing some successes over time among people whose illnesses used to be incurable or unpreventable, the possibility of recovery has now nearly become an expectation for many. Medical professionals and advanced cancer patients alike have been found to perpetuate discourses of hope even amidst severe and poor prognoses (e.g., Delvecchio-Good et al., 1990; Salliant, 1990).

These dominant discourses are found in more public rhetoric as well. First of all, plots of war may be seen in public and healthcare policy discussions. Personal battles with cancer may now be ‘incorporated’ into the larger ‘War on Cancer’ U.S. President Richard Nixon formalized in 1971 when he signed the National Cancer Act, the very first of its kind in the world (Hunsaker-Hawkins, p. 64-65). Even broader still, after a century of two world wars, innumerable smaller-scale conflicts, and pervasive coverage of violence in both fictional and news media, battle tropes are household symbols ready to hand within and well beyond North American borders.

Second, expectations of cure go beyond medical self-confidence. Whether perpetuated by or underlying the telos of cure, many Western discourses of health put forth a “commandment” to “get well” (Rimmon-Kenan, 2002, p. 14). While illness is acknowledged to be a life disruption, and sometimes a severe one, there seems to be an overwhelming cultural desire for an eventual return to ‘normalcy’ defined in terms of health and happiness (Gough, 2005; Rimmon-Kenan, 2002; Smith and Sparkes, 2011). Frank (1995) identifies these discourses as part of a larger “modernist project” to render life events predictable, manageable, and neatly tethered together (p. 83-84).

Fictional narratives and social discourses shape one another. On the one hand, the “happy business” of much contemporary media and cultural activity may be said to cultivate this dominant perception of life without enduring strife (e.g., Howe and Strauss, 2000). On the other hand, many researchers see the trends of fictional media as part of a larger public practice (at least in North America) to preserve a false sense of hope, optimism, and self-esteem among today’s youth and young adults (Polly-Eisendrath, 2009; Savage et al., 2006; Twenge, 2006). It is noted, for example, that there is some resemblance between the favoured protagonists of fiction and the dominant image parents are said to paint of their children. Most films seem to draw “attention on courageous, even heroic deeds” meant to inspire shy youth (Howe and Strauss, 2006, p. 254). These images are reproduced by a common parenting style of instilling an inflated sense of heroism and self-admiration within children, convincing them they are exceptional among their peers (Howe and Strauss, p. 345-360; see also Young-Eisendrath, 2009).

These larger public discourses about how to interpret adversity, limitation, and illness seem to translate into imperatives of narrative coherence and self-authorship. The “generic happy ending,” says bioethicist Rebecca Garden (2012), is a convention that hangs over the heads of

people living with conditions “for which there are medical interventions but no cure—such as chronic illness, disability, degenerative diseases, and the psychological sequelae of these conditions” (p. 122). Due to the focus on individual exceptionalism, an excessive amount of control and, in turn, blame is placed in the patient’s hands, what historian Michael Ignatieff (1998) called “medicalized individualism.” Jungian analyst Christina Middlebrook (1998), in her cancer memoir, referred to this discourse as a “bootstrap theory of illness”; one is expected to hoist oneself up from travails of disease by sheer force of will. Those who are confident in themselves are believed to be able to self-determine the course of their illness whether by lifestyle change or positive thinking (Becker, 1997; Bell, 2010; Delvecchio-Good et al., 1990; Mathews, 2000; Mount, 1993). As shown in chapter 2, more specific oncological discourses of young adult cancer also tend to emphasize individual responsibility and power over other possible factors such as social-structural barriers to proper care and the co-authoring participation of health care workers (see e.g., CCS, 2009; CIHR, 2009; McGoldrick et al., 2011).

In sum, the above dominant discourses may foster certain kinds of illness narratives. Battle and recovery narratives seem to be among the most perpetuated prototypical plots in medical and public discourses, accentuating the battles involved in illness and promising “happy” endings for those ‘exceptional’ and ‘motivated’ patients who transcend statistical predictions and poor prognoses. To be sure, many of the young adult narratives expressed heightened self-confidence, speaking of battles unequivocally won and recoveries impeccably achieved, and often attributing them to being a “rare,” “ideal,” or “unique” patient among others. But, these claims were often tempered by some degree of modesty, especially around perceptions that they were comparatively better situated than other people or simply “lucky.” As we turn next

to the dominant genres within my participants' narratives, we see some similar and different trends between them and the above discourses.

Comparisons and Conclusions: Young Adults' Dominant Moments of Meaning

In the two previous sections, we saw that in popular fiction young adults encounter a wide range of war, journey, mystery, and recovery plots, while in medical and public rhetoric they are more often exposed to battle and recovery narratives. We may conclude that battles and recoveries are the most dominant discourses available to young adults. Interestingly, that does not straightforwardly translate into the hierarchy of genres in the narratives I studied, which took the following sequence from most to least dominant: 1) journeys, 2) recoveries, 3) battles, 4) mysteries, and 5) chaos. See Figure H3 for a visual representation¹¹.

Let us further compare the cultural contexts of fictional and non-fictional plots with the noticeable trends within my sample of young adult narratives. Above all, I found in my research that many more cancer patients emplotted their experiences along moments of sojourning than along moments of fighting, which was somewhat unexpected because of the pervasiveness of battle plots in medicine, public rhetoric, and fiction, as well as in other illness narrative research (e.g., Thomas-Maclean, 2004; Whitehead, 2006). To be sure, moments of fighting were abundant in the young adults' narratives, but their richness and frequency were comparatively diminished to moments of sojourning.

Some people went so far as to repudiate illness narratives of war. For example, a few mentioned the controversy around New Democrat Party leader Jack Layton's death, in which some public backlash resisted media constructions of his death as 'losing a battle' because it

¹¹ This hierarchy was determined by two techniques of analyzing the narratives: first, by studying the frequency of metaphors and narrative sequences that signified a particular genre; and second, by comparing and contrasting those moments of meaning to the overall plots of the narratives. Thus, for example, while many people made frequent reference to "fighting" cancer, these metaphors seldomly endured beyond passing mention or harmonized with the dominant genres of their stories. Thus, it has a lower place within the hierarchy.

implied personal weakness and failure (see the *Globe and Mail* article on this issue; Weeks, 2011). The languages of war were unattractive or problematic for some, who instead preferred journey narratives. Perhaps this trend marks a growing resistance among cancer patients (and physicians too, as the *Globe and Mail* article suggests) to talk about illness in terms of fighting, a shift in dominant constructions of cancer.

Some of the other trends may also lend credence to this possibility. Though not as salient, moments of inspecting and disordering were quite common as well, despite contradicting cultural expectations of order and predictability within medical (and public) rhetoric about illness. These narrative forms have received relatively less academic attention than the other genres discussed, but recognition of their prevalence is growing (e.g., Frank, 1995; Gough, 2005; Rimmon-Kenan, 2002; Smith and Sparkes, 2011; Thomas-Maclean, 2004; Whitehead, 2006).

According to some cultural theorists, contemporary illness narratives demonstrate a loss of power within modern medicine to influence patients' perceptions of illness (e.g., Couser, 1997, p. 11; Frank, 1995, p. 5-12) and, by extension, its imageries of war and recovery. This case may be made for battle metaphors, but I am not so convinced narratives of medical recovery are losing ground because they were nearly as common as journey narratives. Admittedly, some kinds of healing—serendipitous and transformative, for example—were not always endorsed by the young adults' care providers. But, it is possible that young adults involved with the healthcare system are still heavily influenced by the dominant discourses within, but may be for whatever reason more receptive to plots of recovery than of war.

It is hard to say whether these trends signify departures from particular prototypical plots, but they do suggest a decentralization of meaning in which multiple cultural sources and forms are competing for a chance to be taken into young adults' stories. Consuming a wide range of

media, fictional and non-fictional, young adults may be doing extensive digestive work to absorb these numerous influences into their own lives. The perceived dominance of journeys over battles may just be a momentary flicker of favouritism, or a local preference among young adults, or it may be an indication of a larger transformation genres within illness discourses. Maybe the diverse fictional plots inspire young adults to a greater extent than the more selective non-fictional plots, leading to more multiplicity of forms.

Though there may be such underlying social changes in language, there may also be more local factors at play. At this juncture, we need to consider the personal needs and purposes for which individual narratives are constructed, why they may choose the moments of meaning they do. We shall now turn to this concluding analysis of narrative purposes.

Illness Narrative Purposes: Innovative Uses of Prototypical Plots

Looking to the “Language of ‘Doing Something’”

The contexts of narrative construction help place young adults’ stories within larger cultural discourses, but there is more to narrative moments of meaning than their ties to prototypical plots. Narrative forms are also mediated by local experiences, needs, and applications, as some feminist critics of genres have pointed out (e.g., Personal Narratives Group, 1989, p. 102). No story is a simple rehash or exemplar of a prototype, but “an original production, a new existence” even if it is situated within limiting narrative environments (Ricoeur, 1984, p. 69).

This is part of the larger indeterminate processes of negotiating dominant discourses with lived experiences, of converting social conventions or the “practico-inerte” of narrative forms into personally meaningful stories or narrative “praxes” (Sartre, 1960/1968, p. 173). Studying narrative form, writes Ricoeur (1984), demands we try to “understand both *the language of*

'doing something' and *the cultural tradition* from which proceeds the typology of plots" (p. 57; my emphasis). I have laid out the latter in the previous section, and here I consider the many innovative ways in which sedimented meanings are used and transformed in order to 'do something' or achieve some purpose.

This final section is intended to demonstrate, via extended analysis of three narratives, the innovative uses of prototypical plots to communicate individual purposes and needs. To begin with, I discuss some of the purposes that may be served (or not) by the above prototypical plots. Next, divergent uses of these plots are shown within the stories of Tim, Dani, and Rose, bringing out the deeply personal aspects of life with cancer. Although the three stories are reconstructed through my own words and analyses, I tried to use a fitting language to the imagery expressed in their telling to me.

Purposes that Prototypical Plots may Enable and Disable

Narrative genres may be used for nearly uncountable purposes (see e.g., Charon, 2008, p. 49, Mattingly, 1998, p. 5, McAdams, 1993, p. 31), and attention to these may enrich our interpretation of individual stories. Often it is the case that "the act of narration is, at least partly, a response to the needs of the present, as distinct from an attempt at a faithful representation of the past" (Rimmon-Kenan, 2002, p. 15). Because I study young adult narratives as *performances*, as expressive meanings, my analyses must go beyond the study of narrative forms to see what forms are used for.

In this final section, I analyze a range of purposes or needs—loosely categorized as emotional, hermeneutical, relational, and practical—that may be satisfied by using certain narrative forms. Let me first clarify these purposes a bit. First, putting form to illness experiences may serve an array of emotional functions such as soothing or consoling anxieties with

predictable plots, establishing a mood or tone for stories, and releasing or expressing strong feelings with evocative imagery (e.g., Aristotle, 1987; Broyard, 1992, p. 20-21; Kleinman, 1988, p. 49). Second, many of the hermeneutical efforts of narratives entail searching to understand, (re)make, organize/integrate, explore or gain insight into selves and worlds by situating them within larger, mythic conceptions of life (e.g., Charon, 2008, p. vii; Freeman, 2010; McAdams, 1993, p. 28-31).

Third, some relational purposes may include making private sensations relatable to people without cancer via familiar tropes, or, on the other hand, communicating different (perhaps even hidden or oppressed) worlds of experience through relatively unfamiliar tropes like chaotic narratives (e.g., Frank, 1995, 2009; Kadar, 1992; Kleinman, 1988, p. 50). Finally, the practical uses of different genres may include a process of practical reasoning, imagining possible futures and options, storying clinical actions, setting and solving problems, and defining the (un)available courses of healing (Charon, 2008, p. 50; Gergen and Gergen, 2007; Mattingly, 1998, p. 2-14; Mehl-Madrona, 2007).

Prototypical plots may be seen as tools for helping us (or not) achieve the above ends in the midst of crisis; however, they may also be limiting in their selective figures of speech, moods/settings, characteristics, trajectories, etc. As I showed in the previous section, some plots have become more popular than others, which may broaden their intelligibility to larger audiences but may also overshadow other, perhaps contradictory, plots of life with illness. This is especially problematic as narrative forms that “may seem constructive and therapeutic to one patient or writer (or to his/her readers) can be destructive and further traumatizing for others” (Teucher, 2003, p. 1). It is important to consider the ways in which dominant narrative forms may carry these “enabling” and “disabling” effects (Hunsaker-Hawkins, 1993, p. 24).

It is important to enter more extensively into individual stories, as this approach helps to expose some of the demands of people's local situations, as well as the innovative ways they negotiate those demands narratively. I chose exemplary narratives from three participants because they accentuate different moments of meaning and the many personal purposes for which they may be used. First is Timothy, who was treated for brain cancer in his late teens and whose story highlighted moments of mysterious symptoms and medical recoveries. Second, Dani constructed much of his early twenties in terms of personal journeys and athletic achievements as he went through a diagnosis of acute lymphoblastic leukemia (ALL) and then, during treatment, two concurrent strokes. Third, in her late twenties Rose was diagnosed with cervical cancer; struggling with disruptions and wounds that continued into the present day, there were many chaotic moments of disordering expressed within her narrative. I explore each of these stories in turn and discuss what possible purposes may have been enabled or disabled by their particular use of prototypical plots.

A) Timothy: Enabling Endings with Moments of Inspecting followed by Healing

I talked with Timothy a few years after he recovered from brain cancer surgery. He had already graduated high school, entered the world of work, and put some distance to the year he writhed in pain from severe migraines. He was keen on concise sentences and modest descriptions of small-town adolescent life: "Just like anyone else I was enjoying life, I did whatever I liked, asked my parents, you know, I am gonna go to this party wherever could you give me a ride and pick me up, whatever dude, being responsible." His patient, man-of-few-words demeanour reinforced an image of slow-paced, low-stress living.

When his headaches first appeared nothing seemed radically different, just a bout of migraines that made climbing staircases a dizzying activity. But when the headaches throbbed

everyday for three weeks straight, when he could neither walk around nor get a moment's rest, Tim and his parents started to worry. These symptoms were needle sharp in his agonized head, but mysterious to his foggy mind.

His family doctor offered no relief, confounded by Tim's condition. So back to bed he went, and back to the unanswered questions that riddled his thoughts. Without a diagnosis, Tim attempts to understand his situation were potholed with ellipses. His only recourse was film, a medium that came closest to representing the extent of his agony. All he felt he knew was that he was dying:

The next two weeks I either laid in my death bed or the couch with the feeling of paralysis by fear of the excruciating pain that could be triggered by the simplest of movement... The only time I would get up would be to stumble like a drunk to the bathroom so I could puke acid, which would be my only time of relief. I even recall looking up and screaming, caused by the pain, just like the movies.

The biting pulses consumed him, stealing his bodily control and mental fortitude. His vision blurred and his words slurred. He began contemplating suicide, for a time the only foreseeable escape: "I was, like, starting to think I should just go out into my dad's shop and drill a hole in my head to release the pressure, just end it."

In these moments of mystery, Timothy was setting up a particular mood, an emotional setting within which to place his suffering; his reference to film implies suspense and horror, while the mention of suicide shows us an acute moment of despair. These signifiers help audiences to relate to Tim, inviting them to imagine unimaginable pain, but they also lent Tim a framework for understanding. Thriller and horror movies often emplot suffering as an infliction brought on by the aggressions of another; Tim positioned himself as a helpless victim, lacking control of and, in turn, responsibility for his suffering.

Within the context of young adult cancer, mysteries may also perform another notable function. Often in oncology literature, as discussed in chapter 2, delays in diagnosis and treatment are more common among young adults than other age groups, and this is typically seen as a result of young adults' procrastination or non-compliance (see e.g., CCS, 2009; CIHR, 2009; McGoldrick et al., 2011). To be fair, some of my interviewees admitted they avoided the doctor's office because they were too afraid, busy, or ignorant of what their symptoms could mean. But, in the case of Tim along with a much larger majority of young adults, medical judgments often got in the way of good care. Whether by lack of evidence, knowledge, patience, attention, or respect, many physicians did not initially act on the young adults' health concerns¹². From young adults' perspectives, mysteries were often perpetuated by medical staff who were slow to listen and quick to judge. Though Tim was not intending to criticize his physician for sending him home with severe migraines, that his mysteries were extended by that decision adds a critical element to his narrative.

Tim boasted of withholding his urges to take hold of his father's drill long enough to attend a CT scan—"I just fought through it and came out on top"—at which point the mysterious dark of his pain was flooded with light. He could see where he was—very close to death as it turned out, a fast-growing brain tumour discovered at the eleventh hour by a rescuing faculty of medical technicians and physicians. As he was hastily swept into surgery, Tim claimed he was suddenly no longer afraid or doubtful:

I just stayed calm, you know, [and said] thank you for telling me what was wrong with me, let's get me fixed...And I didn't worry at all, I knew I had people around me that would do everything they could for me, so, I was just happy, looking forward to the next day where it would be better and next day and next day to the point that it would be all over and I'd be alright.

¹² Erroneous assumptions often underlined these dismissals, for example, that young people don't get chronically sick, don't know their own bodies, are hypochondriac or depressed, and so on.

In what seemed an instant a moment of inspecting mysterious symptoms leapt into a moment of medical healing, similar to the time sensitive plots of film Tim drew upon in his time of agony. The suspect was identified, caught in the act by the illuminating CT scan. With the name and remedy in the hands of professionals, Tim spoke of feeling deeply reassured and relieved. He never once retrospectively questioned their authority, even when they initially sent him home with little more than riddles and pills. This unflinching trust endured from surgery to weeks of radiation treatment and then months of chemotherapy.

When asked if cancer changed his identity at all, his response was blunt: “Nope. I am who I am and *if anything* it’s made me a better person...healthier, more caring, live life to the fullest” (my emphasis). Such commentaries on his own life are a testament to his convictions that he was cured. This story of what he saw as “triumphant” healing builds upon an unwavering confidence in the power and predictability of medical interventions.

Like his use of mystery plots, Tim’s medical recovery narrative placed the burden of pain and healing outside of himself. His disease was constructed as ‘other’ to him and as having very little to do with his spiritual and moral lives—unlike many journey plots or transformative recovery plots. This is a very welcome dissociation for people who do not wish to believe cancer is a disease of the soul. As with the cause, so too the cure; his healthcare teams acted upon his body, “fixing” him, relieving him not only of unbearable pain but also of having to interrogate his role in his cancer’s etiology and remission. Medical interventions were constructed as the defined course of healing, a path toward restitution, a preferential ending instilling hope within Tim and promising recovery to others who place their trust in oncology.

Though Tim’s narrative enabled hope, consolation, and understanding, it carried with it some restrictions. For example, his narrative was demonstrative of how much weight can be

placed on simply naming cancer. In the mysteries of film and books, typically the climax is the time leading up to discovery of ‘who done it’ and the dénouement is the quick capture and cessation of the culprit’s schemes. Applying this structure to chronic illness experiences can be problematic, for it seems answers are often conflated with solutions. Diagnosis can be just the beginning, which may disappoint and further distress those expecting it to be the final ‘scene.’ Furthermore, not all problems in medical care are, in fact, solvable (e.g., permanent disabilities, surgical complications, chronic fatigue, etc.); these enduring disruptions seem to conflict with Tim’s narrative (and many others) where all questions (purportedly) get answered in the end.

Some of the limitations of medical recovery narratives also come out of their attempts at normalcy and coherence. Tim’s story ends with restored health and happiness, an expectation that is not always attained by people with chronic illness and may, in Tim’s case, conceal enduring complications from having cancer in a very sensitive area. A growing body of medical discourses and cancer memoirs from patients (some of whom are young adults) are endorsing nearly unconditional recoveries (e.g., Carr, 2007; Zammett, 2005). With external and internalized pressures to become well again, Tim and many others may construct their stories in these terms, possibly subverting some underlying physical or emotional needs in favour of social needs for acceptance. Enduring anxieties, recurring pains, late side effects of treatment, or other ongoing troubles may be discouraged as a violation of decorum.

In the “language of ‘doing something’,” we may say that Tim’s story was enabling distance from and an ending to his cancer experiences, while disabling conversations about possible enduring mysteries and unachieved recoveries. Some of these themes re-emerge in the next narrative, although by way of different plots and for different purposes.

B) Dani: Acceptance and Agency within Moments of Sojourning and Fighting

In terms of life circumstances, few people would differ from Tim more than Dani; and yet, their stories rang with some familiar tunes. Dani immigrated to Canada from Asia as a young child and had lived in one of Eastern Canada's metropolitan cities for most of his life. For him, growing up was a complicated matter, rife with "testing my boundaries," "exploring the world, trying new things and seeing what life had to offer." After high school, he was "ready to adventure" into unfamiliar territories, seeking "opportunities to learn" about himself and his surroundings. Though three years had passed from his diagnosis of ALL to the time we sat down to an interview, between chemotherapy and physiotherapy his recovery "regime" filled all but the last six months of that time period.

Committed to fresh foods and elliptical trainers, Dani believed he followed a "healthy" and "active" lifestyle. He was rather surprised when he started cramping up and had trouble breathing. He went immediately to the doctor and was—unlike Timothy—quickly diagnosed with ALL. He was numb with shock at first, but primed with adventurous instincts and bored with his current life path he was, oddly enough, looking forward to the escape: "For awhile, ha, I actually enjoyed going through treatment because I didn't, I did not enjoy school...I really was looking for a way out and cancer took me out of that. I didn't have to worry about anything...It felt like a vacation." More parallel to Tim, he was under the impression illness is temporary and, as with most vacations, he expected it would end far too soon. This claim foreshadowed a rude awakening to the severity of Dani's condition:

One day my, my arm just raised up on its own and I was just, I was just eating lunch in my bed and my right hand was active and all of a sudden I wasn't even paying attention to it but suddenly my left arm just raised high above my head and I couldn't move it. I was just, it just stayed there so I buzzed my nurse and, ha, I was still in a good mood I was like 'Nurse, I have a question' and I couldn't move my wrist so I was just waving my

hand and she's like 'Well you can put your hand down' and I was like, 'That's my question, why can't I?'

Dani had had two strokes, which left his whole left side paralyzed. Though he tried to maintain a "positive demeanor" the vacation was over. His moment of sojourning had taken a turn for the worse, becoming a moment of banishment, leaving him in a world he had not anticipated or desired. "Because of all the side effects of the medication in chemotherapy...I decided to do all the, the medication first before I focused on the physical rehabilitation." That meant "my life was on hold for three years" until chemotherapy was over. This was a time of "mood swings," isolation, and yearning for a "safe place to talk" about his fears. It seemed to him that a journey without movement was akin to a life without living. Dani felt he was "wasting away" in a "surreal" time and place, consisting mostly of "medication, appointments and confinement."

No longer able to carry on a "vacation" kind of journey, he sought out a "sense of clarity" and "acceptance" through a more reflective kind of journey. He spent time working on the anger, depression, and frustration he held toward the place entrapping him. With the help of some available support groups, he sought to break out of his confining sphere of "negativity." Recognizing his suffering in others allowed him to see he was not "the only bitter human being in this world." Many had to make the same travels, and could offer advice or testimony toward regaining a sense of hope.

This first sequence of Dani's story was emphatically adventurous. His narrative expressed a "sense of estrangement and 'otherness'" (Hunsaker-Hawkins, 1993, p. 87), the sentiments of "unhomelike being-in-the-world" that health researcher Fredrick Svenaeus (2000) described as integral to illness experiences. Dani's moment of sojourning provided a mood predominantly of uncertainty and loneliness but also of curiosity, a desire for and a will to

enforce change. This invitation to be transformed had practical connotations as well, as he positioned his reflective journey toward ‘acceptance’ as a prerequisite for continuing upon the path of rehabilitation.

Physiotherapy requires a lot of stretching and resistance training, and so it may come as no surprise that during this period Dani started to reimagine his journey as an athletic feat, transforming a moment of sojourning into a moment of fighting with one’s own limitations. He worked for eight months on regaining mobility and strength in his weakened limbs. He saw this as a “huge challenge” that he had to “overcome” through the “miracle of exercise.” He was in “training” hoisting dumb bells, pulling ropes, walking on treadmills, and “a lot of planks, a lot of squats.” His mother started his training early, before physiotherapy, by getting him to pay attention to his neglected arm, asking him at sporadic times, “What’s your arm doing?” He continued this training in the gym not only for general use and mobility, but more specifically for a marathon he ran just after finishing rehabilitation.

The marathon was more than just a goal; it was an overarching metaphor of healing. As both athletic achievement and long distant run, a marathon is an obstacle to overcome as well as journey toward a defined end. For Dani, it emblemized a milestone in recovery, a return to his former glory as a “healthy” and “active” person. This image carried forth in his general perception of cancer: “I’ve achieved so much, I’ve conquered my paralysis, I’ve conquered my, my chemo therapy and I’m just continuing to move up a mountain, the proverbial mountain and the physical mountain of, of success and challenge and hardship.” Part conquest, part accomplishment, he presently saw himself on the “other side of the cancer world” and “back in society,” as one who “learned from the ordeals” and could instruct others as a trainer-guide.

In this regard, Dani and Tim seemed to share strong ideas of unequivocal restitution. As Dani said, “Though we [young adults] talk about a new normal, my new normal is the fact that I’ve become normal again.” At some points he depreciated the significance of his cancer experiences: “It was just a facet of my life. It is not the whole of my life.” On the other hand, Dani placed a lot more stress on cancer still being a part of his self-image: “Though I’ve done treatment, I’m done all my analysis, I still feel I’m living with, I’ll, I, I might be living with it for the rest of my life.” This is perhaps owing to his emplotment of cancer as an athletic achievement for which to be proud.

Moments of sojourning were also more frequent in Dani’s narrative, and with them were statements that he had ‘learned’ from his illness. There is a slippery slope to talk of ‘learning lessons’; it can create a social expectation—almost a command—to gain something from one’s suffering and to improve one’s life. Some people do not wish to seek a “sense of clarity” in their suffering, but rather perceive cancer as meaningless pain irrelevant to how they have lived.

Dani noticeably shifted from journey and sport metaphors once he started talking about physiotherapy. Whether as war or as athletic task, narratives of fighting illness are believed to empower patients who may otherwise feel helpless or passive to their disease (Hunsaker-Hawkins, 1993, p. 88). Dani seemed to embrace the agency and activity implied by a plot of war. On a collective level, people with cancer may envision a sense of camaraderie common to army soldiers who train together, hold similar ranking, or fight in the same battalion. Dani found this team in other young adults he knew who had cancer. However, his fight was often individualized, as a personal exercise in strength and endurance.

The constructed path toward healing was, contrary to Tim’s, a matter of patient labour and training. Dani imagined a very different, but still hopeful, trajectory that enabled him to ‘take

charge' of his well-being, to participate in his own recovery. Please understand, in no way do I see Dani's interpretation of healing as preferable to Tim's. I do not necessarily favour more 'agentic' constructions of narrative identity; I am rather more interested in "agentivity" (Bruner, 1990, p. 118-119), how agency is distributed differently in narratives and what that means for praxis. In these juxtaposed narratives, Dani bestowed more agency upon himself, implicating *his* actions in his recovery to a much greater extent than was the case for Tim—according to whom the actions of his *medical staff* were more essential.

My critical evaluations dwell less upon the therapeutics of agency (toward which I have demonstrated my suspicion) and more upon the limits of fighting languages. For some patients, healing is not facilitated by imagining one's body as a competition or battlefield between conflicting entities (Hunsaker-Hawkins, 1993, p. 66). In Dani's story of training, personal commitment seemed to be a determining factor in healing, which may segregate or disallow expressions of ambivalence and doubt as inimical to recovery. Emotions outside of courage and resolve—including the acceptance Dani said he pined for prior to these moments of fighting—may be implicitly judged as reservations of the cowardly or precursors to surrender (Teucher, 2001b, p. 169-170). There are also, as mentioned earlier in this chapter, problems with saying the deceased have "lost" their battles.

These first two stories both express restitution in post-treatment time; with Dani in particular we can see expressed needs for understanding his purpose and place in the route toward 'normality,' in the process disabling more ambivalent voices about assigning personal meaning and responsibility to survivorship. Maybe these two stories derive from an authentic account of the facts. Maybe they come out of people's optimistic wishes for a clean bill of health. Maybe they originate in strong expectations that survivorship stories of cancer must have

hopeful endings. Whatever the case may be, Rose stood out as someone who did not fit these standards.

C) Rose: Destabilizing Narrative Order through Moments of Inspecting and Disordering

When I interviewed Rose, she was a year out of treatment for cervical cancer and two years since her initial diagnosis. She unabashedly disclaimed promises of medical recovery or hopes of discovering existential benefits from her cancer journey and, for this reason, may be seen as a counterweight to the more chipper stories above. Rose hailed from a small town and, for her as for Tim, nothing quite matched rural living. She couldn't stay away for long, always ready to return to the intimate charm, calm streets, and open fields.

Not to say she spent her time absorbing the ambience of conversing crickets and setting suns; she said, "I was always busy with something so I didn't really have time to really reflect on anything." She worked hard toward the life she had envisioned, though sometimes it felt like a delayed journey: "Well, at first things were all going on the right path...[but] even before diagnosis [my] time lines kept shifting back (C: Right, yeah.) so the expectations I had um, going into I guess my early 20's they had to change." These "time lines" represented some of the more 'traditional markers' of adulthood—especially getting married and having a family—that were introduced in chapter 2.

Rose shared with Tim an extended moment of inspecting rather odd bodily changes her physicians could not effectively interpret. Rose was sure she was incontinent for several months. "Embarrassed," she sought medical help and was told by a bladder specialist that it was nothing: "the specialist actually treated me horribly...she did, like, her exams and she diagnosed me with something else, um, told me it wasn't, there was nothing she could do for me and I'm gonna have to just live with it." A few months later she returned with more leakage, and though the specialist

“rolled her eyes,” she referred Rose to a colleague. She had a biopsy and after a weekend sitting in suspense was told she had cervical adenocarcinoma, a glandular cancer that had kicked secretion production into high gear.

For Rose, identifying the perpetrator was no real consolation; it had infiltrated her body and would not be taken without taking in return. She lost her chances of childbirth as her uterus and several lymph nodes were cut out, a tremendous blow to her vision of the future: “having my family, like, that’s what I’ve been wanting my whole life since I was like a teenager.” Her next CT scan was clear, meanwhile her thoughts were muddier than ever: “I never really thought much about having cancer, more about what the cancer took from me. I felt like damaged goods and that I had lost part of my identity as a woman, even now though the emotional aspect is still something I struggle with on a daily basis still.” As her moment of inspecting shifted from mysterious symptoms to a criminal plot, cancer appeared as a thief who robbed Rose of her body and identity. Solving the mystery of its activities saved her from losing much, much more, but it also revealed the extent to which the tumour had embedded itself within her being.

Post-treatment she felt she was getting “back on track” with the guidance provided by loving family and friends. That is, until a year after her first diagnosis: “Follow up appointments always put me on edge and at 12 months, I received a PET scan. The PET scan revealed a localized tumor and 2 positive lymph nodes; radiation and chemotherapy was my next adventure.” In her clinical consultation, she had “too much information and too many emotions to process”; she left this appointment of bad news thinking, “What just happened?”

Her thief had returned and this time had made it even more difficult to apprehend: “There was nothing more [the surgeons] could take,” so they had to employ other arresting technologies: four rounds of Cisplatin, twenty-eight rounds of external radiation, and two rounds of internal

radiation. The urgency with which her oncologists planned this tactic did not allow for time to save her eggs (her last, though remote, hope of having her own biological children). She was hastened into the medical system before she could absorb the full shock of it:

I got really emotionally upset with, with um, the first time with not being able to carry children and then I was gonna do like the egg freezing and then it came back and then I couldn't put the treatments on hold and then I lost that.

Like so many other small town patients, chemo and radiation meant frequent trips to the nearest city, and in Rose's case, she had to move into an urban centre she had no desire to be in, cut off from her main supports. And along the trail to and from the hospital was a continuing series of irreparable losses. So much so, she said, that "I no longer consider myself whole."

In contrast to the earlier two stories, Rose's narrative is relatively more chaotic: it did not expound miraculous changes of fate, or redemptive purposes to suffering, or a neat ending that reaffirms the normalcy of health and the transience of illness. Rather, she told a story of still being in illness, of being a perpetuate victim of its appetites, and each time walking away with less flesh and less life:

I can definitely say that this is not where I thought I would be in my life, but life happens and there is really nothing you can do to change it. I struggle daily with the emotional aspect...again not of having cancer or the treatments themselves, but more what was taken away and the hopes and dreams that I lost. There are days that I don't even know why I am even alive. Don't get me wrong, I am not suicidal...rather somewhat depressed as to not knowing what my purpose is in life... What I need is someone to tell me what my future holds, but I won't be holding my breath for that to happen.

Rose seemed in search of a journey, one that would lead her out into more clearly marked paths, predictable weather, and bearable obstacles. She asked for guidance, for purpose and dreams, for life to take on an orderly character. To be sure, she was not in total chaos; she spoke of having a job she loved, but tempered her pleasure by admitting she uses the distraction of work to blot out her sadness.

It is the comparatively strong sense of enduring mystery and chaos that crowns Rose's story as an exception, perhaps as a deliberate dissent, to expectations of narrative order. However, her story is distinct only by degrees, as many moments of disordering may be found across the young adults' narratives. Her hesitation to overshadow her distress with redemptive rhetoric should be a teachable moment: that we don't get so caught up in our search for narrative patterns that we start to normalize them.

This last point brings us to the different purposes of chaotic narratives. Narratives involving chaos, or what psychologist Dan McAdams (2006) called "contaminated plots" that reflect "problems in life movement" (p. 219), are often perceived as the opposite of restitution or redemption (Frank, 1995, p. 97; McAdams, 2006, p. 211). Indeed, Rose's narrative expresses difficulties in how to proceed in light of the many disruptions incurred. She communicated a need to escape her present disorderly life, to find a path leading toward healing.

There are, however, other purposes revealed in how Rose used chaotic plots that suggest more is going on than a simple inability to find order. Chaotic narratives may instigate reflection on some of the most strongly held expectations of their audiences (Frank, 1995, p. 97). Moments of disordering wriggle into the cracks of narrative forms and split them apart. By speaking of enduring mysteries, interim recoveries, and disorienting journeys, Rose exemplified the instability of narrative order, the frailty of sedimented meanings, and the customary concealment of incomprehensible experiences. Chaotic narratives may be, in fact, marginalized and relatively invisible due to the seemingly critical attitudes they present toward dominant discourses of illness and healing; they may be one of many "outlaw" genres of storytelling, vilified or avoided because they transgress the rules set out by more dominant genres (Egan, 1999, p. 14).

Rose's chaotic language also criticized established forms of narrative and knowledge. In a more intentional way than for Tim, she demonstrated that mystery and, indeed, chaos can be perpetuated by inattentive care providers. She reversed the typical narrative about delayed diagnosis in young adults, affirming that negligence cannot be attributed to people like her who have had to "fight to be heard." Her story contradicted dominant genres about the possibility of restitution, recovery, or any foreseeable "lessons" from having cancer—even while she mentioned her *desire* for such things. We could read her moments of chaos as a failure to reach an ideal, or as the failure of an ideal (i.e., narrative order) to apply to Rose's experiences; I am more inclined toward the latter in my attempts to legitimize marginal stories of chronic illness.

It seems that, for her, the critique of narrative coherence was more important than the dream of achieving it. One of the main limitations to chaotic storytelling is the impact it can have on audiences. Frank (1995) called for "enhanced tolerance for chaos" (p. 111) because it remains difficult to be heard when one's story violates customs and expectations for talking about illness. Those seeking social validation may not always find it. Some researchers have found chaotic stories can elicit fear, anxiety, and discomfort among some audiences, as well as prescriptions for how to get out of chaos (e.g., Smith and Sparkes, 2011)¹³.

As Rose herself has admitted, she has "no one to talk to" because friends and family cannot seem to hear her story. While moments of disordering her life have served to reveal marginal ways of thinking about illness and the follies of dominant genres, the ability to *communicate* her story, to acquire an audience, may be damper because of the 'outlaw' nature of her narrative.

¹³ The most commonly reported suggestions were to seek therapy or the support of others, remove social and structural barriers to proper care, and entrust in the powers of modern medicine (Smith and Sparkes, 2011).

Conclusion: The Subjective Stakes of Narratives

Without delving into the idiosyncrasies of a particular story, we may recourse into thinking of narrative genres as abstract, categorical entities. Individual stories bring different forms to life, they anchor metaphors within tactile situations and challenges. The narratives of Tim, Dani, and Rose enrich an array of images of young adult life during cancer as they employ different moments of meaning toward divergent ends. Attention to form brings out the symbolic meanings of their stories, but attention to purpose links form more intimately to praxis. We see what their stories are ‘doing,’ for them and for their audiences. In individual stories we may see the varying values of narrative agency and order (the former of which I address more extensively in the following chapter). This shows that the personal stakes involved may go well beyond the desire for self-authorship and narrative coherence. We may see the creative ways in which young adults interpret and address the existential challenges of crippling pain, chronic disability, thwarted life goals, and prospective death. Above all we appreciate the subjective stakes at the heart of each person’s story, the service of which different narrative forms are engaged.

Chapter Conclusion: Innovative Narrative Forms and Purposes

Use of generic categories in clinical or therapeutic settings must be premised on the assumption that narrative form is fluid, up for negotiation, and dependent upon context and purpose. Taking into account both the values and limitations of different prototypical plots, it seems that no form of storying cancer can say it all. Telling a particular kind of story brings forth certain experiences more easily than others. Battles, journeys, recoveries, mysteries, and chaotic moments of disordering all have a valuable place in constructing images of illness. Perhaps this is why we see synthesis of multiple genres in young adults stories of cancer; they bring in

divergent plots that portray cancer as sometimes predictably ordered and sometimes unexpectedly complex.

We also need to appreciate that this diversity is not, strictly speaking, a free-for-all; in medical and public rhetoric in particular, we encounter some genres more often than others. Innovative narrative forms are produced through negotiating sedimented meanings with personal needs. In order to appreciate this dialectic between narrative forms, contexts, and purposes, we must take into account both the intersubjective plots that link young adults' stories together and individually rich moments of meaning.

Narrative Identities as Moments of (Non)Being

“[I]n order to make you understand, to give you my life, I must tell you a story—and there are so many, and so many...How tired I am of stories, how tired I am of phrases that come down beautifully with all their feet on the ground...I begin to long for some little language such as lovers use, broken words, inarticulate words, like the shuffling of feet on the pavement.”

—Virginia Woolf, *The waves*, p. 137

Introduction

One of many powerful passages in Virginia Woolf’s beautiful novel *The waves* (1931/2012), the above quote prefaces an attempt by Bernard, one of six main characters in the book, to tell his life story. He seemed to be voicing some contempt for stories, or at least a suspicion that stories may be too neat, too singular, too structured to get anywhere near what we call our ‘selves.’ Woolf’s editorial choice in who speaks this criticism is quite significant, as Bernard was known by his friends to be a great story-teller. He was, in fact, attacking the adequacy and relevance of his own craft. He questioned grand narratives with all “their feet on the ground” but still high in the sky, abstracted from the shaky floors of experience. Through Bernard, Woolf called for a “little language,” much smaller stories unrestricted by a single, overarching plot or identity, offering only slippery spaces for our toes to stand unsteadily upon.

The waves is a fictional text and perhaps its criticisms of narrating life do not extend to autobiographical narratives. Indeed, some stronger proponents of narrativist theories of self argue that people’s stories about themselves *are* their identities, insofar as stories are essential to their being (e.g., Baddeley and Singer, 2007; McAdams and Logan, 2004) or are the “very medium of our existence” (Randall and McKim, 2008, p. 8). I harbour little doubt that people’s

self-stories are important to understanding who they are, and if Virginia Woolf found them entirely worthless she would not have also been a prolific non-fictional writer. Narratives are, however, not the only medium of self-making; people constitute themselves through a wide variety of symbolic expressions, including not just stories but also visual self-images (e.g., fashion), bodily gestures, everyday activities, life projects, etc.

More importantly, some emerging narrativist traditions more convincingly argue that narrative identities are partially fictional in that they are imaginative and constructive (e.g., Bruner, 1990; Freeman, 2010; Hunsaker-Hawkins, 1993; Mattingly, 1994; McAdams, 1993; Ricoeur, 1985, 1988). As with narratives genres, people's identities are constructed through a dialogic process of innovation and sedimentation (Ricoeur, 1984, p. 68), creatively interpreted and located within a dynamic world of possible lives. People's stories use and negotiate different identities, drawing on different cultural forms as they try to make sense of the ebb and flow of crisis situations.

There are many ways to make identities, each with their own limitations, and I offer no privileging defence of narratives as producing truer, more coherent, more authentic or otherwise better selves. Corresponding to my performative understanding of identities, I see narratives as putting forth "moments of being" (Jackson, 2008; Woolf, 1938/1985, p. 79), shimmering reflections in the rough waters of life that are both illuminating and distorting, and always fleeting. This angle may be particularly apt for cancer research as experiences of severe illness often entail "narrative wreckage" (Frank, 1995, p. 68) threatening to sink a "self-in-crisis" (Hunsaker-Hawkins, 1993, p. 17-18). In recognition of the instability of identities it is also necessary to discuss "moments of non-being" (Woolf, 1938/1985, p. 79), the absence, ambiguity, or play of orderly identities, the uncontained liquid depths from which patterned waves of being

arise. My intention is to seek not a deep, unmoving floor of being but its rippling surfaces, the rising and falling identities reaching the shores of my perception, all the while taking in the motions of young adult life during cancer. Figure I1 (in Appendix I) outlines how this perspective on narrative identity follows my larger theoretical framework.

In this chapter I explore narrative identities in four waves. The first wave reintroduces and applies the concept of liminality to moments of (non)being in illness, touching on each of the phases of separation, struggle, and consummation (Turner, 1966). The second wave builds on the previous chapter with regard to some pertinent narrative forms and narrative environments; in particular, I review the influence of mythic characters from different prototypical plots within the young adults' moments of (non)being. Third, I situate these mythic identities within the young adults' depictions of their social relations. In particular, I consider how moments of (non)being and meaning are intersubjectively constructed within interactions that are sometimes amicable and sometimes oppositional.

The fourth and final wave moves the discussion into mythic conceptions of young adulthood, including the "traditional milestones" of development (i.e., independence, career, marriage, family, etc.) defined by many psychologists and psycho-oncologists as the apex of adulthood (e.g., Decker et al., 2007; McAdams, 2013; Roberts et al., 1997; Zebrack, 2011). I address how the young adults negotiated these idealized identities and what that may mean for thinking about identity and generativity among young adults living with chronic illness. Throughout this chapter I critically engage with the ideological construction of young adult identities, exploring the extent to which young adults used mythic identities to reintegrate disruptive experiences into a unified identity (narrative coherence) and reconstruct themselves as agentic actors (self-authorship).

Transformed Being: Liminality and Cancer

Reintroducing Liminality

Severe or chronic illness can produce liminal selves wherein one's perceived positioning in local social worlds is disrupted, reinterpreted, and renegotiated. Liminality is often talked about as a process of rituals and practices (Turner, 1966); this definition pertains to employment as well. Indeed, as I argued at the end of the last chapter, narratives may be seen as purposeful activities or "praxes" intended to mediate and move beyond restricting conditions (see e.g., Charne, 1984; Sartre, 1960/1968). I apply liminality to my analyses not only as a descriptor of personal and social experiences of cancer but also as a poetic device, a literary frame for speaking of disrupted and transformed being over time. In this context, I discuss liminality as narrative sequences—comparable to moments of "disequilibrium" described in literary theory (e.g., Todorov, 1968/1981, p. 50-51)—including the sequences of a) separation, b) struggle, and c) consummation.

A) Separation

Within rituals of liminality, the first sequence of "separation" begins when some revelation or reversal of circumstance leads to a shaken sense of self (Turner, 1969, p. 94). It should come as no surprise that for all the young adults I interviewed, their diagnoses marked most acutely their sense of separation from who they once were, what sociologist Michael Bury (1985) referred to as a "biographical disruption" of illness. This "shock," a term many used, was constructed as a visceral experience through metaphors of bodily impact, likened to a "knee to the goods," being "hit by a bus," or witnessing an "earthquake." Diagnosis also separated them from people with whom they previously affiliated; they were set apart from the majority of other

young adults, and the general population at large, who had no chronic illnesses and held very little consciousness of their mortality.

Some people may see this separation as a release from all obligations or social roles, a moratorium of sorts¹. For instance, literary critic Anatole Broyard (1992) came to believe that his cancer was a “great permission, an authorizing or absolving” from responsibility (p. 23). To be sure, some young adults talked this way about the beginnings of their treatment. For example, readers may recall from last chapter that Dani, an ALL patient in his early twenties, initially saw his chemo treatment as a “vacation” from an uninspiring time in university; he changed his mind, of course, when he had a stroke. Martha, who had Non-Hodgkin’s lymphoma (NHL) in her late twenties, noted that nobody in her local world expected her to play a supportive role to them: “for the first time in my life, family and friends didn’t rely on me for anything. Even the train wrecks.” In both examples, they reported a sense of respite from responsibility, in a way a refreshing escape from their former lives.

However, this moratorium was often described as temporary. Before the shock of diagnosis barely set in treatment plans were discussed, planned, and executed. People had to adjust to a new set of routines very quickly as medical appointments became the order of the day. Simply getting diagnosis often involved blood tests, follow-ups, ultrasounds or CT scans, more blood tests, more follow-ups. Once treatment began it only got worse. The sheer number of times each person had to come in and be poked by needles necessitated installation of PICC lines or Hickman lines (both central venous catheters). The young adults were entangled in a new life schedule dictated by medical procedures.

¹ I discuss moratoria at length in chapter 2 as a socially sanctioned time of exploring different identities often seen among adolescents and young adults (Marcia, 1973).

People with full time jobs or other commitments had to put them aside in order to attend six-hour chemotherapy appointments several times a week (usually with a weekend ‘holiday’). Each ‘round’ of chemo was usually a few weeks long. With the average number of chemo rounds being 4 to 6, and sometimes coupled with radiation treatments (once a week for several months), it is no wonder participants felt their lives taking on *more structure* during treatment, as opposed to the *anti-structure* that is said to inhabit liminal spaces. Hospitals had their own social structures and the young adults became immersed in them through regular contact with their staff, policies, and interventions.

Because of the breakneck speed of intervention, the majority of young adults said they had not really digested or comprehended their diagnosis until after treatment stopped. In sum, they were too preoccupied with the regimens of their treatments to reflect on larger existential questions. Then, the new routines of treatment halted as quickly as they began. With the tempo of post-treatment life slowing down and appointments reduced to 3- or 6-month follow-ups, people finally had the time to reflect on what was happening. Thus began the second phase of “struggle” or liminality proper.

B) Struggle

The time *after* treatment often replaced the rushed, practical mindset, what some called “survival mode,” with a reflective awareness of their transformed and transforming being. At this point in their narratives people encountered identity crises, recognizing above all the bodily toll of treatments. Weight gain or loss, fatigue, sensorimotor dysfunction, visible scarring, and other noticeable body changes demanded reevaluation of their self- and body-images. Faced with damaged bodies, they had to renegotiate to what extent and in what ways their selves depended upon their bodies. They also talked about trying to figure out if they were on the same path in life

they followed prior to cancer, or if the experience had sent them on another course. Finally, they considered where they were in relation to those around them, perhaps as reintegrated equals, delayed travelers, involuntary deviants, lost hopes, and so on.

It may seem strange at first glance that people would feel *more liminal* in post-treatment. Surely the young adults “struggled” in the midst of chemo or radiation, but their troubles became more recognizably existential once they acquired the uncertain status of being ‘finished’ treatment. Were they still part of the hospital or not? Were they well or still ill? Were they cured or dying? Being released from medical care can seem more ambiguous than being admitted because nothing is really being done about the situation. Common long-term and late effects of cancer can further this ambiguity—chemo brain, physical disability, and the like—because of their chronicity and their possible allusions to an imminent recurrence. Emotional and existential issues can also be ‘chronic,’ repeatedly encountered and rarely ever resolved, complicating the process of “consummation.”

C) Consummation

The “consummation” phase is most problematic in this context, as nearly half of the young adult narratives did not exhibit a strong sense of ‘aggregated’ identities. Finding where one fit in seemed an ongoing effort, a chronic negotiation. Many doubts and obstacles stood in the way. The majority of participants had not reached five years post-treatment, and as that is often used as a goal post in survival statistics for determining whether people are ‘in the clear,’ the young adults may have been holding out their votes of confidence until then. Some also talked about new problems, like late emerging pain from surgery, which foreshadowed more possible disruptions in the future. Most were still dealing with emotional distress and existential questions—not knowing their place in the world—few of which found assistance in their cancer

care centres or local social worlds. Some young adults still hadn't returned to work, a few of whom hadn't finished treatment. In light of these moments of uncertain and transformative being—what may be more accurately called moments of non-being—it could be said that post-treatment identities do not always end in consummation.

None of these points are meant to criticize the participants for 'failing' to reconstruct stable narrative identities; it would be anathema to my ontology of identity to demand more extended or unified moments of being. In addition, couching this liminality in terms of failure does a disservice to the creative ways people reinterpreted their identities and the merits they attributed to being in liminal spaces. To their credit many young adults reinterpreted themselves in meaningful ways, or were content to live in a time of uncertainty (as the most likely certainty would be a terminal prognosis). Frustrations aside, their illnesses enabled new ways of thinking of themselves. See Figure I2 for a visual of liminality in relation to cancer experiences.

The following sections extend discussions of liminality by relating them to the use of mythic figures to make sense of selfhood during illness. Across these debates we see a wide range of liminal and non-liminal identities produced out of the young adults' negotiations.

Mythic Moments of (Non)Being: Prototypical Emplotments of Identity

Narrative Forms and Illness Identities

Larger mythic stories, or master narratives, are internalized and reinterpreted as people make sense of their own lives (Charme, 1984; Hammack, 2008; Hunsaker-Hawkins, 1993; McAdams, 1993). Religious and existentialist scholar Stuart Charme (1984) aptly described this process as the "sacralizing of the self" (p. 4), the interweaving of personal identities with cultural myths. In the previous chapter, I demonstrated how prototypical plots and personal purposes are brought into innovative moments of meaning. An extension of that basic premise is that people

may use mythic figures and characters from different narrative genres to place themselves within larger plots of action, from the shock of diagnosis to the attempt at consummation in post-treatment. Working with the different narrative forms I have already discussed—battles, journeys, recoveries, mysteries, and chaotic stories—I show how myth and personal experience come together in their expressions of narrative identity². In this context, I make the distinction between a) less liminal moments of being and b) more liminal moments of non-being.

A) Less Liminal Moments of Being: Heroes of Perseverance and Force

Though used in a variety of ways, the following characters positioned the threats of illness as temporary and reparable. These identities emerged at times when participants displayed a sense of normalcy, recovery, or resilience in the face of disruptive transformations, thereby accentuating less liminal (more consummated) moments of being. Thus, we see identities positioned as “heroes of perseverance” and “heroes of force,” characters that Arthur Frank (1995) located within particular narrative forms³ (p. 134). As moments of (non)being alongside moments of meaning, the young adults’ identities tended to parallel the kinds of plots they used to story their illnesses.

Perhaps the most common performances under this heading were “heroes of perseverance,” constructed to signify an ability to endure ongoing and life-threatening adversity (Frank, 1993, p. 119). These identities affirmed that whatever obstacles or disruptions may arise in a person’s world, they may be overcome or accommodated. Among the most familiar identities in cancer discourses—often seen in recovery narratives but also in journeys and mysteries—‘*survivor*’ identities seemed to be the most highly contested among young adults.

² I am by no means implying these associations with mythic figures are delusions of grandiosity; though some young adults found heroic demonstrations in their confrontations with illness and mortality (and I will not deny them that either), the majority conceived of themselves modestly as doing what anyone would do or as doing not much of anything worthy of praise.

³ For example, he situated heroes of perseverance within journey stories (p. 129).

Survivorship suggests that one has persisted; though changed somewhat, one has ‘lived through’ a perilous experience. Some participants, like Lindsay living with Hodgkin’s lymphoma, argued the term ‘survivor’ should be reserved for those who suffered “most,” those “who were worse off, the ones who have to go through bone marrow transplants or who (pause) lost something or is not curable.” Quite a few young adults shared her sentiments, and if they did not see themselves as suffering ‘enough’ they would object to being called survivors. Contrast that with Jerry, a young man with brain cancer who held a broader notion of ‘survivor’ simply meaning ‘not dying’: “I feel like a survivor, I just, I don’t know what else you could say. Just, I guess it wasn’t my time.” Although ‘survivor’ was a familiar identity to most participants, they had very different ideas about who it applies to—who, in effect, ‘really’ had a crisis that they had to ‘endure.’ Thus, people varied widely in the extent to which they applied the term to themselves.

Sometimes in illness narratives—particularly in the prototypical plots of medical recoveries—selves and bodies are separated out and the latter are lent to medical scrutiny, surveillance, and modification (Frank, 1995, p. 84-88). During such *moments of healing*, the young adults were often positioned as ‘*patients*’ who may be seen as ‘passive,’ helpless, or resigned to powers beyond themselves, a humbling appreciation of their limited control. More agency was attributed to medical personnel or, in more serendipitous recovery stories, to the capricious whims of chance. This may not be an inspiring image for some people living with a serious illness⁴, but it articulates an important aspect of many people’s experiences. One of Kairol Rosenthal’s (2009) young adult interviewees summed it up best; Geoff spoke about how he could not take credit for his recovery at all:

⁴ For instance, in a recent interview about her memoir of living with cancer on the CBC Radio program *Q*, feminist playwright Eve Ensler said that becoming a patient seemed too much like “stopping,” inhibiting a transformative experience—a “cancer conversion”—she said she invited. People who are not interested in being changed dramatically by their illness may perceive ‘patienthood’ in a very different, more favourable, light.

Everyone thinks that survivors are fighters. I don't think I really fought for my life. I laid there and got doped out of my mind for six months and got well, while other people were sitting around reading Bernie Siegel, doing their imagery work, and died. (p. 94)

With discourses of visualization and psychosomatic healing being passed around in and out of cancer centres, some patients may feel they must be somehow involved in their own recovery. Geoff's comments resonated with a few of my participants who talked about just "laying in bed," waiting for their treatments to take effect, believing the route to healing required little effort on their part.

Resignation to medical intervention is a theme in various parts of every participant's narrative. Not a single person refused medical treatments in favour of more 'participatory' approaches (like imagery work), though some negotiated what treatments they would accept, others complemented mainstream medical care with alternative approaches, and a few ended treatment because their care providers believed it was more likely to kill them than would their cancers. For the most part, people communicated 'trust' in the capabilities of their care providers, putting faith in modern medicine to preserve their self-images by saving their bodies. But, the divisions between bodies and selves could not always be sandbagged; changes in one sometimes leaked into the other. Patient identities were not necessarily free of transformation, only mediated by confidence in medical care to mend anatomies and selves.

Participants emplotted their experiences quite differently when telling of *moments of fighting*, which implies more resistance and agency than given to patient identities. Many people who are ill ascribe to this positioning as they have a "strong aversion...to the idea of themselves as victims" (Hunsaker-Hawkins, 1993, p. 65). This aversion can come along with fears of being judged for not appearing to try hard enough or of not displaying a sufficient demonstration of defence (Rimmon-Kenan, 2002). Those who seem to be engaging in battle are often

commemorated in public discourses as militaristic '*warriors*' or "heroes of force" (Frank, 1995, p. 134).

Warrior identities were present to varying degrees in many of the young adults' narratives. As noted in chapter 4, battle stories were not nearly as dominant as journey or recovery narratives; as a result only a few people heavily and consistently evoked war-like identities. Two women positioned themselves frequently as divine warriors, "chosen" by God to resist cancer's evil advance. Laura, for instance, believed that cancer went beyond her individual case of colorectal cancer. She constructed the disease as a widespread, corrupting plague that requires mobilization of all those affected to "beat it." She pitched individual suffering as a social problem with a collective solution—not a contained fight on a cellular level but a cosmic war between good and evil.

The young adults sometimes constructed themselves as '*detectives*' or 'vigilantes' when mysterious events required investigation and, for whatever reason, they felt responsible for seeking answers. These identities often emerged in *moments of inspecting* when undiagnosed symptoms exhibited themselves as mysterious signs, when care providers seemed to get caught up in 'red tape' and other bureaucratic entanglements, or when they did not attend to patients' complaints. For instance, Linda said she was frustrated by "things that never came up, you know, that really should have, around menopausal symptoms, around all kinds of things like that that were just not mentioned any where by anyone, no literature no website no nothing." One example she gave was of something to conceal her PICC line. She decided to do her own research: "I went online and...I Googled cast covers." She discovered that "there are different companies that offer lovely covers that will cover up your PICC so that you look, you know, not

like a medical refugee when you walk down the street.” Her own investigations helped her to address “issues around appearance...that really weren’t mentioned” in her clinical consultations.

When participants had to ‘sell’ their caregivers on what they had found in their investigations, they often positioned themselves as ‘*advocates*,’ a special type of heroes of force. They talked about having to be strategic, charming, or manipulative in order to win a war of words with their physicians. More necessary than brawling with their care providers was oratory persuasion and use of medical knowledge to achieve the best care possible. For example, Lorena wanted to change the “face of lung cancer” as perceived by her care providers and the public at large. She combated this image with critical statistics: “Not many people know that up to 25% of new [lung cancer] diagnoses are never smokers, but we have to live with the stigma all the same.” Her use of medical knowledge *against* medical and public perceptions of her cancer is typical of many initiatives undertaken by the young adults in order to protect and preserve their lives.

Social conflict sometimes had the wrong connotation for participants’ struggles. Instead, they placed themselves as ‘*athletes*’ pushing to the limit their resources and abilities in order to overcome adversity. Linda, for example, felt uncomfortable talking about cancer as a battle, but found it quite helpful to imagine herself as running a marathon: “you just keep your eye on the ball, you just keep going and going and going and it’s painful and it’s exhausting and it’s unpleasant but you have a lots of people around you.” The struggle was redirected internally, as a test of strength and will to surpass her own self-limitations.

Whether heroes of perseverance or of force, or both, people made use of mythic figures to make sense of the demands of particular situations. They produced what philosopher of autonomy Catriona MacKenzie (2008) described as “practical identities,” temporary selves

serving certain needs and performing selective praxes. There are important differences in “agentivity” (Bruner, 1990, p. 118-119) here, which demarcates who needs to act and in what ways. Survivor, patient, warrior, and detective figures were all performances of less liminal moments of being, in their own ways trying to preserve selves-in-crisis through narratives of endurance, patience, or resistance. Whether the participants were disputing claims that cancer forever changes a person or were trying to salvage what remained from the chaos, less liminal identities expressed both the need for and the prospect of protecting selves-in-crisis from further disruptions.

B) More Liminal Moments of Non-Being: Tragic and Transcendent Figures

Sometimes the young adults’ identities embodied moments more reflective of non-being or transitional being. Tied to mythic figures of transformation, they expressed episodes of change and, in some instances, desires for change. These more liminal moments of non-being affirmed a foundational vulnerability of lives, worlds, and especially selves. We may think of them as ‘decentered’ or de-positioned selves (Heidt, 1991) constructed to communicate selves-out-of-order or selves-in-the-midst-of-rebirth. It may help to discuss two different ways in which mythic identities foregrounded people’s expressions of liminality: tragic and transcendent figures.

The first and most familiar were ‘tragic figures.’ Not surprisingly, cancer was often portrayed as an agent of destructive change, inflicting mischief upon participants’ self-perceptions, alienating them from their bodies and from others, and demanding critical evaluations of things they took advantage of in life. In more extreme situations, cancer was constructed as more malevolent and deliberate in its intrusiveness, a mysterious and threatening ‘thief’ who came in one heavy swoop or in a series of calculated returns to take fleshy bits of their being. As Rose described of her cervical cancer and treatments (first introduced last

chapter), she was left feeling “robbed,” “damaged,” and “not whole.” In such *moments of inspecting* participants positioned themselves as ‘*victims*’ who had lost treasured parts of themselves to a conniving villain.

In more tragic moments of non-being people portrayed themselves as being at the mercy of their life circumstances, pushed and pulled in different directions until stretched out. They sometimes became hapless ‘*exiles*’ uprooted from their homes and banished to foreign lands, initiating *moments of sojourning* neither invited nor desired. The young adults talked about being “disconnected from society,” “physically and socially isolated,” in an “other world,” and sometimes literally relocated to an unfamiliar place closer to cancer care centres. With each new telling of disruption, these tragic figures appeared as more and more fragmented, dissociated from themselves by erratically “undisciplined bodies” (Frank, 1995, p. 104-108) and by social segregation.

Other identities expressed moments of non-being without being necessarily upsetting transformations. These ‘transcendent figures’ referred to liminal forms of being that seemed to overcome, alleviate, or convert into good the violence cancer experiences inflicted upon them. For example, when emphasis was placed more on self-involvement in recovery narratives—and less on being compliant ‘patients’—people often positioned themselves as ‘*self-healers*’ or co-healers. They constructed more intimate bonds between their bodies and selves, where the latter were seen as responsible to the well-being of the former. Over half of my participants suggested their cancers signified a need to change some part of themselves and they felt an urge to “engage” with their experience or participate in its process. This often came out of recognition that their former identities were already destabilized by illness and suffering, but with a hope that their involvement would transform them.

The ‘work’ of self-healing involved peeling away extraneous layers of the self, coming to what Hunsaker-Hawkins (1993) described as an image of a “real self” (p. 34), a perceived spiritual awakening or discovery after an arduous trial or travel. Like an onion molding on the outside, the discarded parts of selves were considered corrupt or tainted. Some people spoke to even deeper transformations of self, rebirths often metaphorized as a “*phoenix*”⁵ (Frank, 1995, p. 119-124, p. 135; Rimmon-Kenan, 2002, p. 24). Whether facilitated by invasive and intense cancer treatments or by personal attempts at “conversion” to instigate change (like those of Eve Ensler above), selves would undergo a process of purification.

In order to be purified, the flaws of the past had to be confessed. Some participants saw being “selfish,” “careless,” “naïve,” or a “workaholic” as factors leading either directly to cancer (e.g., not taking care of their health) or to later regrets and emotional turmoil (e.g., not spending enough time with family). At least two-thirds of the participants mentioned evolving or wanting to evolve into a “better,” more “authentic” or “organic” self. For instance, a married man in his forties, George, spoke of being profoundly altered by his experiences of acute lymphoblastic leukemia. He believed that it is “virtually impossible” to leave cancer behind and “pretend it never happened.” Claiming that cancer transformed him into a more compassionate person with a very different set of values and priorities, he confidently asserted: “I am pretty fond of who I am now.” Martha also touched on the continuance of liminality and how it is not necessarily a demoting process:

It’s also taking me a lot longer to sort of move through the transformation to a point—like I’m still constantly changing, and that’s not necessarily, like in many ways (pause) in many ways, with the exception of some of the longer term health issues, it’s really for the better. Like I, I’m definitely a better person.

⁵ While Rimmon-Kenan (2002) describes the phoenix in terms of recovery narratives, Frank (1993) assigns them to quests (p. 123-124). It is fair to say that they may come in a variety of forms within a diversity of narrative forms; as with prototypical plots, narratives identities may leak into one another.

Martha maintained, as did many others, that her moments of non-being led ultimately to moments of transcendent being and, in that way, she cherished her liminal experiences.

On the other hand, some moments of de-positioning involved a more deliberate effort to deconstruct singular or unifying notions of self. We could refer to such elusive characters as *tricksters*, who often in myth (see Hyde, 1998) and in illness narratives (see Frank, 2010) subvert a cultural order in order to expose its limits and lies. Whereas tragic figures in cancer stories usually showed intercepted desires to achieve consummation, tricksters often exposed consummation as an ideological concept that fails to recognize the messiness and uncertainty of selfhood in illness.

Tricksters are sometimes desired for the relief they provide to exceedingly orderly presentations of life. They seem to be the kinds of characters Kairol Rosenthal (2009) sought out in her study of young adult cancer, as she had an intentionally critical desire to break out of cancer patient stereotypes. She wrote, “I had grown tired of images of cancer patients smiling with gratitude. I cringed when I heard stories of strength and hope, not because they aren’t important or real, but because I experienced a flip side that is never spoken about” (p. 90).

Rosenthal is surely not alone in calling for other voices in dominant discourses, with the aim of illuminating more liminal moments of non-being during illness. Lung cancer patient Lorena used herself as a saboteur of common assumptions about her disease: “What does the face of Lung Cancer look like? Well it looks a lot like me, young, non-smoker, asymptomatic, and healthy—well, except for the cancer...Gone are the days that we can associate Lung Cancer to only smokers or those who have been exposed to second hand smoke, because it is an injustice to those like me who were neither.” In this and other situations, young adults used tricksterly

figures to position themselves as de-positioned selves, disrupting common myths about who gets a particular disease by bringing attention to the limits of understanding.

More chaotic characters like those described within this section often rub against our expectations and hopes; they serve as challenges to narrators and audiences alike, both of whom are grappling to understand what is going on and to whom it is happening. Tricksters, for instance, have been noted for their critical function in deconstructing dominant discourses about illness (e.g., Frank, 2010). In many ways, these tragic and transcendent figures issue a note of caution to audiences—myself included—who sometimes err in expecting to see stable or consummated moments of being. Even thinking of narrative identities as ripples or waves can presume a patterned flow of selfhood, which may only apply when the seas of life are at ease, the winds calmer, the currents weaker. Liminal selves may be steeped in waters at the roughest times of day, or in locations that are never completely at rest.

Conclusion: Mythic Identities in Illness Narratives

Many different identities can be constructed out of cancer patients' applications of cultural forms onto their experiences (see Figure I3). They communicate experiences as well as expectations of illness, lived selves as well as ideal selves. Expectations are not a single image but changing horizons, and as such are manifested in different colourations of selfhood over the course of each narrative. These mythic identities could be used to position oneself within the stages of liminality, bringing to light how each person confronts and refigures the experiences of shock, struggle, and/or consummation.

In her study of adolescents with cancer, nursing researcher Roberta Woodgate (2005) described an array of ways of being among adolescents with cancer, some of which parallel the above identities: perceptions of being a “klutz” seems similar to *trickster* identities in

destabilizing order and balance in life; reports of feeling like an “invalid,” “zombie,” or “alien” express some *patient*-like identities, where their bodies prevented them from doing much beyond resting and waiting to get better; and the sense of “renewal” from feeling like a “kid” again in post-treatment resonates with *phoenix* identities in their similar imageries of rebirth. In her research, as in mine, the need to recognize diverse and fluid moments of (non)being is key, for they communicate an array of biographical and existential challenges brought on by living with cancer. Furthermore, we must take into account how these mythic identities are socially negotiated or co-authored with other important characters in the young adults’ life stories. Let us enter these intersubjective spaces.

Narrative Intersubjectivities: Negotiating Emplotments of Being and Meaning

Peaceable and Hegemonic Lived Relations

I have lent a great deal of attention to the cultural materials young adults used to construct moments of being (and meaning), but here I take into account the many specific hands that assisted in building their identities, the more *and* less cooperative “lived relations” between people that partially define individual “lived experiences” (e.g., Good, 1994; Scheper-Hughes and Lock, 1986). I place the young adults’ moments of (non)being within contexts of these different ‘narrative intersubjectivities,’ demonstrating the co-authorship involved in expressing their existential and biographical challenges.

The challenge lies in how to portray these interactions. Philosopher of social science Michael Crotty (2003) described two dominant ways of representing intersubjectivity, as a “peaceable” world of cooperative exchanges versus a “battleground of hegemonic interests” (p. 63). These two positions amount to a hermeneutics of understanding and a hermeneutics of suspicion, respectively (see Ricoeur, 1976). I display both moments of ‘working together’ and

‘working in opposition,’ making the case that the hinging factor seemed to be the extent to which people were able to bridge their different horizons of expectation about young adult life with cancer (see Figure I4). I relate such moments to three important intersubjectivities within the young adults’ narratives: clinical relationships, local social worlds, and cancer communities⁶. These analyses should strengthen the image of being (and meaning) as *negotiations* between stakeholders and with a range of outcomes.

A) Clinical Relationships: Mutual and Disputed Emplotments of Being

In an essay titled “The patient examines the doctor,” literary critic and prostate cancer patient Anatole Broyard (1992) placed high expectations on the person chosen to treat his illness, demanding he or she “combine the role of the priest, the philosopher, the poet, the lover” (p. 54). He weighed his expectations against his initial urologist, and came to the conclusion he was “such an innocuous-looking man that he didn’t seem intense enough or willful enough to prevail over something powerful and demonic like illness” (p. 37). Broyard admitted the unrealistic standards he and many other patients placed on doctors, but that did not stop him from insisting upon such a ‘heroic’ ideal because “whether he wants to be or not, the doctor is a storyteller, and he can turn our lives into good or bad stories, regardless of the diagnosis” (p. 53). Medical professionals contribute to patients’ stories in a big way, with the potential to help or hinder their efforts to construct meaning and being.

The reality of clinical practice is that it is defined by patients’ and doctors’ “horizons of expectation” (Ricoeur, 1985, p. 208-209). Clinical practice follows what anthropologist Cheryl Mattingly (1998) called “therapeutic emplotment,” within which patients and caregivers “create story-like structures through their interactions” that, she believed, are “integral to the healing

⁶ A fourth intersubjectivity requires mention, that between the participants of this study and myself, the researcher interviewing them. However, I withhold discussion of this important social context until the concluding chapter, as part of a larger overview of some of the limitations and implications of this research project.

power of [therapeutic] practice” (p.2). In theory, this is a collaborative effort of constructing a shared story of illness including a projected plot toward recovery; according to Broyard (1992), both patients and physicians have ‘authority’ on illness, a knowledge base built on experience, and “there should be a place where our respective superiorities could meet and frolic together” (p. 45). In terms of the above mythic identities, this could mean co-constructed moments of being and meaning where both parties agree that, for instance, they are ‘warriors’ engaged in a collaborative battle against cancer, bringing their respective strengths and ‘weapons’ to the fight.

A number of young adults talked about such exchanges, when their doctors served as supportive casts to their mythic identities. Doctors often appeared (in my words) as *allies* in young adults’ fights against cancer, *guides* along their otherwise lonely exiles, *co-investigators* in their searches for answers, *technicians* working on their bodily repairs, and so on. High praises were given to medical staff who were able to meet the young adults in the intersections between their different horizons, responding to their desired constructions of themselves and their illnesses. Sometimes the young adults humanized their care providers as everyday people, saw them as having “a lot on their plates” and “doing the best they can” already, and appreciated them for all they did. They relieved medical staff of the mythic ‘heroic doctor’ image Broyard put forward, and they were met with more patience when they made mistakes or admitted their limits.

At other times, the young adults reinforced the heroic image. They constructed their doctors and nurses as angelic *guardians* along their travels⁷, *saviours* in their pursuits of recovery, *beacons* of knowledge among clouds of mystery, *warriors* leading the battles, etc. In reference to living with brain cancer, Johnny abrasively put it this way, “Somebody said to me

⁷ Broyard described an appropriate image for this more authoritative figure: “I want [my doctor] to be my Virgil, leading me through my purgatory or inferno, pointing out the sights as we go” (p. 42).

‘Was it your faith in God that got you through this?’ And I said ‘No! It’s my faith in surgeons and chemotherapy, you idiot!’” Among Johnny and many others was an unequivocal trust and “faith” in modern medicine—befitted to patient identities—that often led to a less combative relationship with their care providers.

In less ‘peaceable’ moments, the young adults spoke also of break down when divergent interests got in the way of an agreed-upon therapeutic plot. Often these clashes were spurred on by repelling horizons of expectation, and often manifested as *moments of inspecting* their illnesses independently, *moments of fighting* with care providers, or *moments of advocating* for self-interests (described in the previous chapter). With regard to moments of inspecting, disputes were over how to read the young adults’ symptoms prior to diagnosis. When they entered their doctor’s office for the first time, they exhibited more and less vague signs of cancer: general fatigue, enduring colds or flus, visible lumps around lymph nodes, constant bleeding, severe pain/pressure, etc. Very often the young adults said these symptoms were dismissed or misdiagnosed as imaginary conditions, physical manifestations of stress, or hyperbolic responses to innocuous symptoms, and were offered anxiety medications or psychologist referrals.

Physicians were said to perpetuate the mysteriousness of symptoms by making hasty and questionable assessments; even worse, they sometimes accused patients of manufacturing their symptoms. It seemed to be a popular recourse to explain medical uncertainties as strictly mental phenomena that are not really ‘real’ or only ‘in their heads.’ These emplotments often constructed young adults’ identities as *self-healers*, bestowing responsibility upon them to ‘get over’ the allegedly mental causes of their distress. By contrast, the young adults often saw themselves in these moments as *victims* to the will of some malicious, unknown virus or entity and entrusted their physicians to solve the puzzle of their ailments. Not satisfied with such

constructions, many young adults sought out online information to find more personally fitting stories.

The young adults talked more about *fighting* and *advocating* during treatment time. Physician Rita Charon (2006) noted that very often care providers and patients disagree on the contexts and causality of illness (p. 19); for example, tensions may arise between medical Cartesian discourses that reduce illness to biological processes and phenomenological discourses defining illness as part and parcel to people's being-in-the-world. Medical Cartesianism often emplots recovery as the responsibility of medical personnel and constructs those who are ill as having *patient* identities—without moral culpability for the origins or treatment of their disease. While sometimes relieving, medical Cartesian horizons of expectation can disregard existential questions and denounce moral explorations⁸. Some young adults wanted to engage in these processes and expressed frustration over feeling deprived of choice and a voice, saying their oncologists' preferences were “narrow” and restricted the available plots toward healing.

These are just a few of many examples of arrangements between patients and doctors, some of which worked well and others that generated conflict. The larger point is that the patient-doctor relationship can be divided by obstinate expectations that resist other horizons. Given the differences in dominant genres between young adults' narratives and medical rhetoric (see ch.4), it should not be a huge surprise that they often have different ideas about how to emplot cancer experiences. A common barrier to collaborative therapeutic emplotment was flawed medical assumptions that young adults do not get cancer, leading to an overzealous hermeneutics of suspicion around even the most alarming symptoms and legitimate concerns. The fault is no one's in particular, as these cases demonstrated a breakdown of understanding and communication rather than a malicious attempt to deny care. What we may rightfully

⁸ I provide further analysis of moral disputes around responsibility in the following chapter.

challenge, among physicians and patients alike, are preconceptions of medicine as an impeccable discipline and medical statistics as a “technology of presencing” cancer (Jain, 2007) for they may blind people to the existence of alternative and concealed horizons—in this case, the presence of statistically rare cancers among young adults.

Contested emplotments of identity came out of very different narrative preferences, not just between patients and doctors but also between different patients. For example, some young adults wanted more proactive help (or agency) from their oncologists (e.g., a “never give up” attitude) and some wanted more leniency and patience (e.g., being less “forceful”). They also differed in terms of whether they desired more lateral communication involving collaboration or more hierarchical communication where doctors’ voices carry more authority. It is likely very hard for medical professionals to tailor the process of therapeutic emplotment to these different horizons of expectation. The young adults I studied constructed a wide range of meanings and ways of (non)being as they went through cancer, and it has been no easy task even to make sense of them, never mind apply them in clinical practice.

Medical professionals often get criticized for their contributions to less peaceable relations with patients, and the young adults I interviewed continued this trend with many more examples of conflict than of cooperation. While we may recognize these limitations, care providers must also be given their due when tensions appeared low. The young adults credited collaboration less often to medical knowledge of young adult cancer (though they frequently called for such) and more to simply being heard above the noise of medical statistics that conceal young adult cancer. Among the most cherished clinical practices were: suspending disbelief about the rarity of young adult cancer in diagnostic assessments and enabling the young adults to be participants in therapeutic emplotment when they asked to be.

B) Local Worlds: Inclusion in and Alienation from Home Communities

Clinical relationships were, for obvious reasons, important intersubjectivities to the young adults as they lived through their illnesses. However, the young adults also sought cooperation and support from their home communities or “local worlds”⁹ (Kleinman and Benson, 2006, p. 1674). These significant others not only provided relief (or not) in times of crisis; they also participated in defining crises—for example, shaping expectations of life with cancer as a more temporary disruption or as an extended and indefinite illness; by extension, they contributed to the young adults’ self-perceptions, as future *survivors*, perpetual *victims*, etc. Depending on the extent of overlapping expectations between the young adults and their significant others, the resulting interactions sometimes led to a stronger sense of being part of a community and at other times a further sense of alienation or “unhomelike being-in-the-world” (Svenaeus, 2000).

The majority of participants saw their loved ones predominantly as *guides* along their journeys; typically a parent though sometimes a partner or friend, they cared for the young adults at their most vulnerable, intervened in times of crisis, or offered inspiring wisdom that enabled them to carry on. Their constructions of their loved ones were heavily steeped in journey metaphors, but such images were not limited *moments of sojourning*—just as with care providers, they were sometimes portrayed as *allies* fighting alongside the young adults, *caregivers* helping them heal, and so on. In these moments, the young adults’ emplotments stretched beyond an individual living with cancer to include a community of grievors and supporters.

⁹ These worlds for the most part included family and friends, but they sometimes went beyond home life to include work life (i.e., employers and co-workers) and public life (i.e., people associated through volunteer organizations, community engagement, etc.).

Timothy, first introduced in chapter 4 as a brain cancer patient in his early twenties, constructed his local world as a loving and instructional family: “I’ve always been close with my family. I always listened to what they said and their advice the best I could.” He talked most specifically of his father as a moral and emotional compass. Tim said, “[he’s] always told me that, like, you have to start at the bottom and no matter where you are you’re always going to have stuff you have to stick through and keep going.” In *moments of disordering*, when his throbbing skull induced screams of pain and nausea, Tim seemed to look to these teachings and use them to emplot his suffering as *moments of sojourning*. In this way, his father helped to place an existential framework around his pain, where Tim read himself as a *hero of perseverance*—a narrative identity emphasizing endurance and resolve. For his part, Tim’s dad appeared to be constructed as a *guide* or perhaps a *shepherd*, helping him down the hall when the swelling in his head affected his balance, driving him every time to the nearest city for his treatments.

The young adults talked about how their loved ones suffered along with them, not as observers in close proximity but as extensions of the young adults’ pain beyond their lived bodies. In other words, their distress rippled outward, infecting their local worlds, becoming an illness of social bodies. The young adults often said they thought their families suffered much more than they did, having to face the possibility of losing a loved one and often feeling helpless to prevent it. Family members sometimes took on the burdens of being *healers* or *co-healers* to the young adults, and though sometimes seen as “overbearing” they provided needed financial, emotional, spiritual and practical support. A great many familial relationships and friendships strengthened as the weight of illness was distributed across caring shoulders.

On the other side of these intersubjectivities, the young adults often experienced a double sense of alienation: first from their local worlds by people who would not or could not hear their

existential challenges and, in turn, from their own suffering by not being able to speak of it. In terms of the first form of alienation, which expresses *moments of banishment*, some friends or family disappeared right away after finding out about the diagnosis. Lindsay, who was a Hodgkin's lymphoma patient in her late twenties, spoke about how having cancer "opened my eyes up to the type of relationships I had." Seeing the evasion and awkwardness among many of her friends, she said, "I kind of said what I needed to say to everybody that was driving me crazy or that I really appreciated and they could take it or leave it...the way I refer to it is I cleaned out my friend closet." Expressed as a form of *self-healing*, Lindsay spoke of 'purging' herself of unwanted or inert relationships in order to continue on toward recovery. Her story shows that banishment can be to some extent imposed by others and to some extent self-imposed by confronting (or, for some, segregating oneself from) others.

In terms of alienation from their pain, many of the young adults' complaints seemed to emerge from divergent lived experiences between them and others. More than that, certain ideologies seemed to be at stake during these interactions, where, for example, being young adults with cancer seemed to threaten taken-for-granted assumptions about young adulthood. People who were still present (i.e., not "cleaned out") sometimes pressured the young adults to tell certain kinds of stories, especially *recovery narratives* involving *survivors*. More liminal identities were often discouraged as they did not always promise happy endings or "redemptive selves" (McAdams, 2006).

While they sometimes wanted to be seen as 'different' in the sense of having some unconventional experiences of young adulthood, the young adults were often considered strange in ways they did not intend. For example, their 'delayed' recoveries were moralized as having psychological causes; a friend or family member told them being "positive" would lead to

recovery, and saw their lingering anxieties, frustrations, and doubts (believed to be under their control for the most part) as catalysts for further suffering, recurrences, or death. Peers were unaware that existential challenges can come after treatment and assumed that when treatments were finished it was all “over.”

The young adults said they struggled to negotiate their identities with these horizons of expectation. They claimed to feel they were “not allowed to cry” and had to appear “positive,” feigning composure, optimism, or confidence they did not feel; these veils were for “protecting” and appeasing others who seemed to be unable to handle the more difficult or controversial moments of meaning and (non)being: being near-death, living with tragedy and loss, floating in liminal spaces, contradicting assumptions about health, etc. In these moments, people’s local worlds shaped their identities by encouraging (and listening to) more conventional narratives of illness, and discouraging expressions of alternative, subversive, or less ‘redemptive’ selves. Being alienated from others and from their distress, the young adults talked about having “no safe place” to have uncensored conversations about their experiences.

In sum, the young adults had mixed encounters with their loved ones during their time with cancer. In moments of community, they constructed their local worlds as support networks that helped them to live with and to understand their illnesses. In moments of alienation, their distress did not seem to be cared for or considered legitimate—they were exiled from social life. As with clinical relationships, rigid horizons of expectation made the difference, imposing dubious meanings and identities upon the young adults. The power of discourses of *recovery*, in particular, seemed to estrange young adults from the people they needed to understand and validate their ongoing disruptions. Unless *mystery* and *chaos narratives* gain wider recognition in public discourses, forced isolation may continue to be a strong theme in cancer narratives.

C) Cancer Patient Communities: Shared Needs and Discriminatory Rhetoric

Young adults sought out communities other than their local worlds to help make sense of life with cancer. People from very different walks of life, who had no other line of connection outside of having diseases lent a common name, entered into conversations with each other about how to emplot their illness experiences. These communities of cancer patients took a number of forms: local support groups, telephone or email correspondence, online forums, etc. Local groups were available only in larger city centres, but online communities such as Young Adult Cancer Canada and Cancer Fight Club served urban and rural young adults alike, linking people across and within the country's provinces and territories. At times these connections produced social identities that help contextualize individuals' suffering, while at other times they contributed to a politics of identity that divided and excluded certain people with cancer.

Because of their different locations and needs, the young adults I studied had varying degrees of connection with cancer patient communities. Over half were heavily involved in local and regional/national communities, a third had some contact with other young adult patients, and only a couple had had little to no interaction. With this in mind, perhaps my interviewees represent only those cancer patients who proactively seek out support and information and not those who prefer not to be part of a community of patients, for whatever reason. In any case, the young adults' stories of cancer communities illuminate some of their needs as they negotiated meaning and (non)being. Lorena, mentioned above, talked most perceptively about the values and drawbacks of cancer communities and below I use her rich reflections for examples.

The young adults listed several reasons for building cancer patient communities. Typically, they formed in response to a common need to find other young adults with cancer, others who hopefully understood what such a life was like, who had experienced similar

situations (i.e., diagnoses, treatments, side effects, etc.). In a sense, many of the young adults were looking for mirrors into their own crises, wanting to see themselves in the lives of other cancer patients—ideally, those who lived beyond treatment. The ‘counsel’ of these stories seemed to inform the young adults’ therapeutic emplotment, identifying tips and tricks toward *medical healing* (i.e., information for them to pass onto their caregivers) or *self-healing* (i.e., ways of taking charge of their own care)¹⁰.

Sharing stories also established what many of the young adults saw as an intimate bond or union. Other young adults “connected” with them in a way that medical professionals, family members, or friends possibly could not. In fact, these unions provided an “outlet” for venting frustrations in those other intersubjective spaces. The young adults reported feeling more comfortable and ‘at home’ with other young adult cancer patients, sometimes described as “cancer friends,” taking the place of other friends who had left or who no longer shared the same world. Lorena said she found it consoling to know “I really did have this community of others that were not family or friends that knew me really, really well, but on some level there was this incredibly deep, genuine connection because of what they had also been through.” Cancer communities often combated *moments of banishment*, making new social identities after being *exiled* from others and redefining their personal *journeys* through cancer as collective emigrations.

These communal identities enabled formulation of common purposes for which the young adults became *advocates*, such as more awareness, support, funding, and recognition of young adult cancer. Together the young adults co-constructed ‘distinct’ needs (especially

¹⁰ Sometimes others’ stories served, critically, as a counterweight to the stories told by doctors, providing alternative images of life with cancer. Above all, they took cancer out of the anonymous statistical language that some young adults found frustrating about their medical teams’ narratives, and steeped it within concrete lived experiences that assisted the young adults in imagining their own futures.

survivorship care, fertility consultations, and social support) that they found wanting across Canada. Sometimes they used ‘celebrity patients’ to strengthen their cause, most of the time referring to athletes Lance Armstrong¹¹ and Terry Fox, though occasionally mentioning former leader of the New Democrat Party Jack Layton (not a young adult but a high profile case) and author of *Crazy Sexy Cancer Tips* Kris Carr. Referring to familiar figures could be seen, like use of incidence statistics, as a kind of “technology of presencing” (Jain, 2007), a way of revealing that young adult cancer has a public existence beyond individuals and, in turn, is of public interest.

The young adults observed several limits to this kind of intersubjectivity, though they were mentioned much less frequently than its advantages. Sometimes the young adults simply did not want to be a “part of that world,” which would bring them back to their past suffering, instigate existential questioning and labours to make meaning again, and resurrect faded distress. Some suggested that defining themselves as cancer *survivors* or *patients* or *advocates* years beyond their treatment stalled their personal desires to “move on” from their illnesses and keep their pasts in the receding distance.

Another common limitation was the fact that the young adults did not share certain experiences. Cancer is an umbrella term for over 200 kinds of disease (Buckman, 2006) and though there are some parallels, each type of cancer—breast, testicular, Hodgkin’s, non-Hodgkin’s, cervical, brain—is distinct in many important respects, including but not restricted to growth rates, physical effects, cultural meanings, treatment options, and impacts on quality of life. Some participants said because each cancer is “unique” or “individual,” it was “hard to fit

¹¹ These interviews were before the recent scandal around Lance’s use of performance-enhancing drugs while cycling. Prior to this hermeneutics of suspicion over his achievements, his story was often told with metaphors of conquering adversity, winning competitions, and (with the not-for-profit LiveStrong Foundation) empowering others, inspiring many *athletic* identities among the young adult narratives.

in” into one community, or to feel ‘fully’ understood. In Lorena’s case, she stated that her lung cancer had a worse prognosis, made her feel more exhausted, and was more heavily moralized as self-inflicted in comparison to some of her friends’ cancers. Varying ages, cancers, judgments, challenges, and life situations seemed to be barriers to a sense of sharedness.

While dominant discourses within oncology talk about the ‘distinctness’ of young adult cancer, there are experiential borders that to some extent preclude a cohesive community of young adults. Multiple communities of cancer patients seemed to be needed in order to, in Lorena’s case, deal with moralization of a particular kind of cancer. She said, “even though I had [young adult cancer support] I still always felt there was something that was missing and it was sort of this piece about being a lung cancer survivor and as someone living with lung cancer.” She described how, when she met other lung cancer patients—regardless of their age—she acquired a different “sense of identity” that related to the distinct challenges of lung cancer: “breast cancer survivors find immense power being together with other breast cancer survivors...And so I derive inspiration and hope from these women who are battling the same thing and the same kind of stigma that I’m also battling.”

Lorena was convinced that moral judgments also had created hierarchies of support, where ‘more deserving’ (i.e., less moralized) communities were provided more financial, social, and emotional assistance. She argued that, “lung cancer is very underfunded even though it’s deadly” because of public perceptions that “you must have done something to deserve this.” In these comments, she revealed some of the possible politics of cancer identities, where “ribbon” campaigns (yet another ‘technology of presencing’) hides away other forms of cancer that are—by the statistics—more severe, stigmatized, life-threatening, and in need of improved outcomes.

In sum, *moments of advocacy* can be, contrary to intentions, a divisive strategy for raising awareness, drawing attention to selective truths and needs while concealing others.

At their worst, cancer communities risk becoming ideological and discriminatory, breeding their own forms of alienation. For example, a woman in her forties who had a low-stage breast cancer and uncomplicated treatment, Lee lamented over some tensions within her cancer community:

I was kind of like stuck in the middle of things, in the sense that I wasn't given some, like, perhaps legitimacy by the cancer group...I got away with not having to go through the worse of it sort of, uhm I never had to lose my hair, so I didn't have to go through the whole body image of all that.

Recall from the previous section that some young adults reserved *survivor* identities for those who suffered the most; on the flip side of that perception, Lee said a similar principle was applied to her, that perhaps she did not suffer 'enough' to be able to talk as a survivor.

One prejudice I noticed across several of the narratives, and yet was never externalized as such, was a skewed juxtaposition of younger and older cancer patients. Lorena summarized this judgment best, in her rhetoric of young adult cancer: "A 65 year old might be worried that they can't vacation because of treatment; a 30 year old is worried about loss of independence, fertility, career change and other psychosocial and financial needs due to treatment." Often older adults were portrayed as having more luxurious life circumstances and being relatively unaffected by a diagnosis of cancer. Retirement and pension may alleviate some of the concerns expressed by young adults, but having cancer at an older age is not necessarily easier than at a younger age¹².

¹² For example, Sinding and Wiernikowski (2008) showed that there is a wide spectrum of responses to cancer among older adults, ranging from "biographical disruption" to "biographical continuity." They also mentioned that expressions of disruption were often "foreclosed" by cultural expectations, also seen in the young adults' narratives, that illness is part of the due course of aging and, therefore, of comparatively little consequence.

As members of young adult cancer communities continue to spread this divisive discourse, whatever the intended purposes they minimize the suffering of older cancer patients who share, if not the same age and cohort-related concerns, then similar existential challenges of isolation, loss of meaningful activities, and death (e.g., Hammond et al., 2012). Comparative language, in these situations, became ageist rhetoric for the purpose of directing attention to the crises of young adult cancers.

Cancer communities can be opportunities for young adults to work together and support one another where no other occasions exist. In some ways, they are grassroots movements rallying toward more acceptance and understanding of a population in Canada given relatively little attention or support. In no way do I condone their dissolution, so essential they can be to combating alienation and isolation. Nevertheless, a variety of controversies come to light when we apply to them a critical lens. By identifying and advocating select causes, these communities may do violence to the diverse and marginal voices within their own communities, or they may inadvertently depreciate the suffering of others (e.g., aging cancer patients) who must also compete for limited funding and resources. Whenever we encounter *moments of advocacy*, we should always be careful to consider for whom these promotions are serving and for whom they are doing injustice.

Conclusion: "Our Lives Are Not Our Own"

In a beautifully written and ambitious novel about human suffering and oppression, novelist David Mitchell (2004) wrote that "Our lives are not our own. From womb to tomb we are bound to others, past and present, and by each crime and every kindness, we birth our future" (p. 221). In their social interactions with healthcare providers, families and friends, and other cancer patients, the young adults reported both vindications and violations of their personal

emplotments of being and meaning. These ‘peaceable’ and ‘hegemonic’ intersubjectivities all seemed to give birth to future identities, the former enabling shared visions of selfhood beyond cancer and the latter disabling expressions of socially unsanctioned or deviant horizons of expectation. It seems apparent that the young adults’ moments of (non)being and meaning were not entirely their own, that they formed in collusion with or in resistance to prevailing horizons of expectation within local collectives. When we talk about mythic identities, we must take into account their endorsement and opposition among the casts of important characters within people’s narratives.

The next section expands upon the dialectics of myth and experience, including narrative environments around identity development. We thus come to what has dominated discourses of young adulthood in narrative identity development and AYA oncology, the idea that cancer stalls and sometimes reverses young adult development.

Moving Milestones: Expected Life Courses and Developmental Identities

Developmentalist Discourses as Cultural Myths

Discourses about identity development may be seen as a subspecies of ‘cultural myths’ putting forth an ideal evolution of identity over the life span (Baddeley and Singer, 2007; Burman, 2008, p. 117; Randall and McKim, 2008 p. 51; Rogoff, 2003, p. 161-177).

Developmentalist discourses make up one of many narrative environments under which young adults’ identities may be emplotted. Just as with other mythic identities—*survivors*, *warriors*, *phoenixes* and the like—these developmental identities are socially negotiated and contested within individuals’ narratives.

Among a variety of other myths we could discuss, of most relevance are the ‘traditional milestones’ (i.e., independence, partnership, parenthood, and career) often branded as markers of

young adult identity development. As introduced in chapter 2, the overarching myths governing these milestones are the developmental expectations of self-authorship and narrative coherence within young adult narratives (see e.g., Baddeley and Singer, 2004; McAdams, 2013; McLean and Pratt, 2006). These expectations are myths in the sense that they idealize and order young adult life; although they may give direction and purpose to many lives, they also disregard the many ways in which people depart from these ideals. Within this section I analyze young adults' engagement with these expected life courses and the developmental identities that embody them.

Resistant to the normativity involved in these myths, I conceive of development differently. In chapter 2, I adopted psychologist Barbara Rogoff's (2003) definition of development, as "changing participation in sociocultural activities" (p. 50). Her definition seemed to be based on four justifiable premises for thinking of illness and narrative identity development. First, development is above all a process of on-going transformation; in other words, negotiation is at its centre. In the telling of their narratives, the young adults often produced new ways of understanding themselves and their worlds, adjusting their conceptions of development according to available life trajectories and personal desires. Second, development demands use and manipulation of cultural tools to deal with what is at stake in people's personal and social lives. Myths about young adulthood are among these tools, possessing a certain utility that cannot be ignored; nevertheless, there may be circumstances where other cultural tools (such as the mythic trickster figure) are more capable to the task of emplotting identity while ill.

Rogoff's definition contains a third premise that worships no universal standard (e.g., self-authorship) as the 'purpose' or 'end' to identity development, thus moving away from "deficit models" that enable moral judgments on difference. Instead development is evaluated in terms of its contributions to cultural narratives and practices (i.e., as perpetuating, transforming,

or resisting them). We may say that negotiations of being and meaning are developmental movements in terms not of where they arrive, but rather how they open up spaces of experience and colour horizons of expectation. Placed on equal footing are the various ways in which young adults may make sense of themselves and may talk about having ‘developed’ or ‘matured’ after having cancer.

Fourth, which was discussed above in terms of narrative intersubjectivities, development also involves negotiation within various communities of which individuals are a part. For example, therapeutic employment is the process of co-constructing a developmental narrative of sorts, a projected evolution of illness experience toward an improved state of being. This vision may crumble as hegemonic horizons of expectation stand in the way of cooperative exchanges. In this way, the liminality of cancer can be as much about being in-between the discourses of different local collectives (e.g., healthcare teams, local social worlds, cancer communities, etc.) as about being in-between childhood and adulthood or in-between life and death. What we find with the young adults I interviewed is a notion of development dependent upon negotiating being and meaning with other people.

I interpreted the developmental movements of narratives according to the liminal stages above with an additional narrative sequence included at the beginning, hence the following order of discussion: a) developmental identities *before cancer*, b) *separation* from identities with the onset of cancer, c) *struggle* with identities during and after treatment, and d) *(un)consummated* identities in the present. Let us explore them in turn.

A) Developmental Identities before Cancer

This sequence provides a historical context for the effects of cancer on identity development. I ascertained pre-cancer identities predominantly by asking participants how they

would describe what young adulthood was like for them before the onset of illness. I received an overabundance of meanings of young adulthood both across and within individual narratives, typically expressed in enriching stories and metaphors. The categorizations below are of meaning and not necessarily of people, as a single narrative usually contained a multitude of identities.

To rather varying extents people spoke about the ‘traditional milestones’ of adulthood. Around half of the participants talked about striving to attain independent, work-related, and familial identities. For example, Martha said she was on the “right track” until her late twenties, before being diagnosed with NHL:

I went to university, like I moved away from home when I was 19...I was able to sort of go through those major life markers and sort of gaining those life skills pretty uneventfully, right...I started building a career and, you know, thinking about family.

Some individuals were more specific about these “markers,” believing them to be passed at a certain age, almost as though they are preordained or determined. Recall from the last chapter that Rose said: “growing up you always have like these time lines, so mine was like 25 I’d be married and like 27 I’d have kids.” These “time lines” represented a relatively structured view of young adulthood.

Aside from independence, career and family, health was identified as another cultural ideal, often measured in terms of dietary contents, commitment to exercise, and absence of ailments. Thinking about before he was diagnosed with testicular cancer, Richard said: “I was pretty carefree. Um, I pretty much thought like, you can’t get sick at all. Like you’re invincible (laughs). You get that, especially when you’re young.” Youth was often equated with health, and in retrospect most of the young adults saw this as a dubious connection that fooled them along with their family physicians.

The other half of my participants expressed relatively more doubt and less interest in ‘completing’ the gamut of traditional milestones prior to having cancer. Among them, a few admitted to feeling “pressured” by others to get married, build a career, or buy a house—identities that were not personally meaningful to them. They described themselves as living “unconventional” lives, and sometimes this was construed as a personal choice, sometimes as a result of indecision or feeling lost in the world. They said they were “carefree” or “careless,” committed mostly to “exploring” life by dating, socializing with friends, touring the globe, and not being “settled” down to a structured home life.

Exploring different identities, what psychologist James Marcia (1973) called moratoria, was perhaps the most dominant theme across the board. With or without achievement of developmental ‘milestones,’ and with or without desiring such, most participants talked about young adulthood as a liminal experience of trying on an array of selves, dabbling in both moments of being and moments of non-being. This theme was more prominent in narratives asserting “carefree” attitudes toward life and harbouring few, if any, expectations about adulthood. For instance, Laura attributed her lax attitudes about young adulthood to few social expectations placed on her: “honestly, like, I mean I never felt any pressure to, to do anything or be a certain way... I guess I didn’t really have expectations.”

The sheer number of transitional metaphors used across most narratives suggests the prominence of liminality in young adulthood. The time of life was characterized as “experimentation,” being “carefree,” “always kind of in transition,” a “search” or “quest” to “find yourself,” a “rebellious” or “unconventional” time, having “no grand plan,” encountering “unpredictable” or “constant change,” “learning” who you are, and “setting up” for a future plan. According to some developmental psychologists, these explorations should be on the way toward

self-authorship, the purported task of narrative identity development (e.g., Baddeley and Singer, 2004; McAdams, 2013). While self-authorship seemed to be an important part of these liminal stories, the young adults also valued receptivity or openness to *being taken* in different directions by the unexpected. In other words, the reported transitions in young adulthood included a blend of self-directed and contingent shapings of selfhood.

Co-authorship of young adult life also emerged in many forms: social pressures made explicit by few, criticized by some, and internalized by many; parents who permitted moratoria by allowing their children to live at home into their 30s; spouses who obviously contributed to the realization of some developmental milestones like marriage and childbirth; friends who were, as a younger woman with leukemia summarily put it, “an alternative to having a family”; and many others.

I would, therefore, temper the emphasis within developmental psychology on ‘taking control’ of one’s narrative, as contingency and sociality were often recognized as a necessary part of life. Dwelling narrowly upon the individual as self-creator is like arguing that a fish only moves itself, and the currents of the ocean or synchronized movements of schools serve only as distracting scenery.

Before cancer came into these young adults’ lives, they expressed complicated trajectories of development, rich with idiosyncratic interpretations, alternative visions, and mixed reviews of the freedom afforded by moratoria (see Figure I5 in Appendix I). Taking into account the time before cancer helps us place the biographical and existential disruptions of illness into the context of life histories. Seeing how divided the participants were in terms of their expectations and desires, we can better appreciate the diverse ways that having cancer may have

affected the visions they held of their futures. We can see some of this diversity right from the initial liminal stage of separation in their narratives.

B) Separations from Identities with the Onset of Cancer

Cancer almost unanimously produced destabilization (or further uncertainty) of narrative identities, leading to “unhomelike being-in-the-world” (Svenaeus, 2000): separation or alienation from former selves, bodies, relations, and values. However, the reported degree of disruption, the areas of life most affected, the longevity of disruption, and people’s responses to it varied considerably. Angie, for instance, echoed the title of Kairol Rosenthal’s book on young adult cancer and simply said “everything changes.” As illuminating as that totalizing comment may be, we need to further pinpoint the developmental changes that were most at stake in the young adults’ narratives. In sum, the dominant identities at issue were around bodily health and appearance, social perceptions of ‘normality,’ sexual and familial relationships, and work/financial stability (see Figure I6).

First and foremost, perhaps the most perceptible alterations were problematized relationships between selves and bodies, putting into doubt cultural assumptions of health. These forms of alienated embodiment first began when mysterious symptoms emerged. Then, participants’ body-images underwent radioactive singeing, chemical poisoning, and/or surgical atrophy. With enduring health complications like mouth sores, ulcerative colitis, recurring infections, seizures, chronic pain and fatigue, paralysis, lymphedema, memory loss, arthritis, visual impairment, even a case of foot-and-mouth disease, peoples’ bodies became strange to them for a second time.

Feeling “vulnerable,” losing their independence, and being encumbered by pains or mobility problems, participants’ bodily ailments translated into selves deflated in confidence and

fragile to the elements. Some participants constructed victim identities in response, seeing themselves as “damaged goods,” thinking “less” of themselves, and feeling “betrayed” by their bodies. Those with more severe diagnoses (e.g., Stage 4) felt they were “wasting away,” a “skeleton in the mirror,” seeing encroaching signs of death upon or underneath their skins. Bodily dysfunctions sometimes corrupted the young adults’ perceptions of themselves, and they “grieved” the abilities and selves they no longer had as a result of their estranged bodies.

The sense of separation or alienation encountered by the young adults went beyond felt experiences of their *lived* bodies, such as pain and side effects. They reported another form of separation within social evaluations of their bodies, what may be called their *social* bodies (Scheper-Hughes and Lock, 1986). Nearly all felt judged at some point by the people around them—strangers or familiars—for their tricksterly or iconoclastic nub at cultural expectations of health (whether they intended it or not). They often did not seem to “fit in” because of the selves-in-crisis they projected into public spheres. As a result, isolation and exile came out as a recurring theme, labeled with some harsher self-descriptions like “anomaly” or “mutant,” “freak show,” or simply “Other.” Embarrassed or frustrated with others’ lack of understanding, as well as feeling too ill to be in public, they would often stay home and suffer further social isolation.

To be fair, not everyone described a radical departure from their relational identities, and this seemed to be a feature of having supportive family and friends who preserved their place within the local social world. However, the vast majority of people internalized the alienating distance that cultural critic Susan Sontag (1978) said divides the ill and the well into two segregated “kingdoms” (p. 3). They saw themselves as no longer “normal,” an ideal that usually meant being more social, not sick, working, and having a routine outside of the hospital—in liminal terms, being more integrated or consummated into common, everyday social structures.

Furthermore, unpromising prognoses seemed to prevent people from imagining a future return to normal. Jerry, for instance, said his “prognosis is hard to plan around.” He was given a 25% chance to live five years beyond his glioma diagnosis. He resented that portentous statistic for preventing him from living; it held a dismal sign over his head, of which he could not help but be aware. He expressed frustration that his oncologist used that number, as he was sure it was not based on samples of young adult patients: “it was maybe based on 100 guys that were 80 years old and were in the war and smoke.” He may or may not have been accurate in that suspicion, but he demonstrated how future lives and projects can be caught, tugged and pulled between seemingly deterministic medical stats and patients’ notably more hopeful narratives.

A third significant tribulation among the young adults was ambivalence and uncertainty toward becoming parents. Close to half of the participants faced possible or actual fertility complications. For example, prospects of having spouses or kids were strained by chemo treatments that people came to believe made them unattractive, infertile, and de-sexualized. Some felt “robbed” of parenthood as their fertility was taken away and struggled with sexual practices that had become increasingly more difficult to perform. Even those who could possibly procreate were unsure if they wanted kids, fearing genetic transmission of the disease or dying on their children from a fatal recurrence.

That said, not all of the young adults personally valued parent identities. Catherine, for instance, touched on some common concerns around self-worth in light of not being able to achieve dominant ideals of parenthood. Chemotherapy for her colon cancer put her into premature menopause and she said she contended with whether to see herself as less of a person or a person different but equal to others. She eventually leaned more to the latter as she placed no particular significance on having children; the milestone was more of an external “pressure” than

a personally meaningful pursuit. Nevertheless, across men and women, whether parenthood was important to them or not, many said they were disappointed that the *option* of bearing children was foreclosed—possibly in case, post-moratoria, parenthood become a valued identity.

A fourth set of identities disrupted by cancer related to work. The time and effort required to receive treatment, and to treat the side effects of treatment, demanded time off work or away from school. In some cases, this was not a subject of contention: employers were sympathetic, disability insurance was adequate, and a hefty savings account or wealthy family mediated financial costs. However, those without proper financial or employer support struggled to make ends meet. Parents' homes became a necessary respite as self-subsistence was tough with little income. Furthermore, some people described feeling “guilty” for taking leave and going on disability support, as though they would be judged as lazy or unproductive for not working while sick.

Beyond finances, identities tied to a particular career were also at stake. Disability leave represented delayed or even foiled advancement. For example, Richard was preparing to move away from home for school just before he was diagnosed with testicular cancer. He said: “I was just pissed” and “I was just so depressed. I was so down. Um, cuz I found out I couldn't go to [school] anymore.” Above all he dreamed of developing a career of which he was very fond. He risked spending his university savings on healthcare costs not covered by his insurance, but was fortunate in having a family who paid for most of the exorbitantly priced prescription drugs. After an extended delay Richard was able to commence his studies, a happier ending than most among the young adults' stories. Vocational goals often had to be juggled with needed convalescent time, always with resentment toward the ‘career interruption’ of illness.

In sum, with regard to the above identities, the young adults drew social comparisons with others, seeing themselves as both delayed and disadvantaged. Martha talked about watching others living “normal” lives uninterrupted by illness:

I hit this wall and there was no growth from then till pretty much now. You know, um, in terms of you know, like—and everybody else in my life sort of kept on moving along, like having babies and getting married, whereas I just sort of—you know, the natural way I would’ve progressed and you know, who knows, met someone and got married and stuff. That stuff, it stopped completely, like just, it really, it’s really hard to describe but it’s like I hit a wall (claps) and everything just stopped.

Stuck in what she called “arrested development,” she admitted some jealousy toward those ‘passing’ her on the race toward certain milestones. She repeated a common story of cancer treatment as a standstill, no longer moving toward that which they valued. Up until this point, participants told “narratives of decline” or “death discourses” of cancer that are commonly told within oncological narrative environments (e.g., Hammond et al., 2012). However, this is but one side of illness narratives that were quite multifaceted, and a narrative of decline does not usually account for the ways in which developmental crises are sometimes managed by renegotiating personal and social identities. Though some felt nothing really got accomplished during this time, more saw it as a kind of detour or process required in order to continue on with (the same or a new) life. These “struggle” or meaning-making phases of the young adults’ liminality are expanded upon next.

C) Struggles with Identities during and after Treatment

The young adults faced an array of struggles during and after treatment: trying to reconcile past, present, and future selves; dealing with one foot in the hospital and one foot in the community; facing foreclosed or fading ‘milestones’ while reflecting on new and emerging goals; and, perhaps most resonating across all the narratives, straddling the knowledge of what was normal before cancer and what was currently normal. Their ideas about young adulthood

and development required negotiation, which led to creative solutions to existential questions like “what next?” and “who am I now?”

They constructed practical identities tailored to changed and changing circumstances. The young adults said that while old selves and lives were generally cherished and grieved when first threatened, as time passed and they became more immersed in their illnesses they responded in a number of different ways. Below I discuss three of their most notable struggles: striving to retain or recover disrupted identities, reevaluating and reinventing their senses of self, and ‘finding’ themselves among other young adult patients. In these narrative sequences we see how being and meaning were remade in order to reaffirm the possibility of developmental growth and purposeful activity. In these transitional sequences—moving from disruptive times of diagnosis and treatment to life after intervention—identities began to be reconsidered, reworked, and reworded.

With regard to the first struggle, about half of participants seemed to be most invested in ‘returning’ to some pre-cancer sense of self. Among the most desired returns included body-images restored (back to “healthy” bodies), careers put back on track, and entrance back into the social life of their peers. They talked about these changes in terms of wanting to be ‘normal’ again, or at least to *appear* normal if they could not totally recover their old lives. As an example, even while saying she had no therapeutic image to help her through treatment, Lindsay associated her recovery narrative with the seasonal change from cold, dead winter to blossoming spring:

L: I’d have to say, because my treatment ended in May, spring was all I could think about at the time, just because I knew that was the finish line. Um, but I couldn’t say there was a symbol or anything that kinda that would have helped me get through it.

C: What was it about spring that you were looking forward to?

L: Well, then things went back to normal (laughs). Done treatment, and I can go outside again and it wasn't winter and everything was just kind of in the past.

Spring signified a time of the year when life is renewed, when one's energy and exuberance are restored, and the outdoors become less threatening again. The bad weather of winter melts into a forgotten history and the future brightens with longer days. Though a new year and a new season, what Lindsay seemed to desire was the familiarity of spring, its repetition of predictable patterns. She dwelt upon a hope that the past may be recycled into a recognizable future. She also evoked athletic images, crossing the "finish line" of a race, constructing her treatment time as a trial of perseverance. We may see this as an example of less liminal moments of being that strive to erase traces of liminality, affirming that the thread of selfhood remains intact across life with illness.

A second struggle came out of the narratives, an expression of liminality in which the selves of yesteryear would never meet those of the present. Seeing some developmental identities lost to the past, the young adults questioned the relevance of certain traditional milestones to themselves. Catherine, for example, came to perceive what was at stake quite differently over time. Recall from above that losing her fertility was a minor challenge; on the other hand, losing her momentum toward a profession was a "difficult lesson" for her:

I was really obsessed, like I said, about going back to school and getting a university education and I mean I think I've kind of led myself to believe that I was, I had no worth if I didn't have that university education and a good career...there's no point in getting so worked up and oh, 'I have no self-worth because I didn't go and achieve a university education and I didn't do this or I didn't do that and I don't have my masters'... I guess I'm just a lot, feeling like I'm gonna be a lot easier on myself and not so (pause) so determined to achieve you know, these big lofty goals but just to you know, it's just the small things and just do what's within my ability...And, that, that's been a big one, is identifying that my, my self-worth is not tied to any of those things.

Catherine saw a major personal life path foreclosed and she subsequently reevaluated whether it was important to her identity; if readers recall philosopher Galen Strawson's (2004) language of

self-experiences, she constructed a self that was more “episodic,” day-to-day, unconcerned with a “lofty” or grand narrative thread running continuously through past, present, and future. In these reevaluations the young adults sought out ways to understand how cancer had altered them and what those alterations meant for the rest of life. Some read cancer as a “sign” that they needed to change themselves or change the way they were “engaging” with their cancer experiences—evoking healer and phoenix identities of facilitated self-transcendence. In these interpretive pursuits they came to shift their priorities, prefer different lifestyles, and recognize themselves as exceptions to dominant cultural narratives of how young adulthood should unfold.

A third and related struggle to reevaluating identities was to find social worlds within which the young adults’ new identities made sense. Illness, disability, and mortality are all issues that young adults typically do not expect to confront until later in life. Having sat in uneasily close proximity to usually deferred questions, many of the young adults said they could not pretend to share many of the same thoughts, preoccupations, experiences, or values as their peers. This often led to frustration with others of similar age; Martha’s comments above about being in “arrested development” relative to others shifted in tone over the course of her narrative, to the point where she began to criticize the banality of her friends’ major concerns:

We don’t get each other, and I don’t really want to. Like it’s, it’s just easier if I sort of isolate myself. Um, not that it’s hard to talk to people. I just don’t really have the patience for it. Um, cause in the back of my head I’m like “Are you fucking, are you joking me that this is a concern of yours? Are you joking me?”

For Martha and for most of the young adults, their transformed being was not always simpatico with others in their age cohort, making their struggles typically lonely and misunderstood.

In search of a home for their new lives, nearly all participants sought guidance, information, or just stories from other patients, wanting advice and validation for their negotiated identities. Their reevaluations became collaborative undertakings, each person shaping the other

as they distributed experiences and meanings. Living with ALL, Dani (from chapter 4) described some of his contact with other young adults with cancer as a chance of “just being together and in that space of being young again.” In other words, contact with other cancer patients created a safe community for living out both old and new identities without being judged.

Wherever their struggles took them, the participants started to critically engage with developmental identities expected of young adults. What came out of their searches and dialogues, according to their narratives, were sometimes reconstituted identities and reaffirmed commitments to certain ideals, and sometimes deferred identities and sometimes ambiguous feelings about who to be (see Figure I7). In the final narrative sequence of this analysis, we see the most current status of the young adults’ struggles as they talk about (un)consummated identities in the present.

D) (Un)Consummated Identities in the Present

As mentioned earlier in the chapter, participants’ narratives did not always culminate in a “consummation” of stable identities; their negotiations were often carried into the present tellings of their stories. That does not mean their senses of self did not ‘develop’; even those who continued to struggle with their post-treatment identities demonstrated some syntheses of disruptive circumstances with personal desires. These creative projects catalyzed movement in their perceived trajectories in life and modified their participation in cultural discourses around young adulthood. In their stories of the present, the young adults expressed three different narrative movements of identity from the above struggles: return to a ‘normal’ life, entrance into a “new normal,” and perpetual liminality (see Figure I8).

In terms of return, perhaps one of the most ubiquitous statements I encountered was that cancer was a *part* but not the *whole* of people’s identities. The young adults worried about being

pigeonholed as cancer ‘patients’ or ‘survivors,’ thereby having their identities totalized around their illness¹³. When asked whether life with Hodgkin’s lymphoma had changed her expectations, Linda said, “I don’t think that they’re really different than they were before, um I expect to start a family, I expect to, you know, um, continue in my chosen profession... I really did have a sense of where I was going before and I’m continuing on that same path now.” With a urostomy bag Penny knew some areas of life were going to be complicated: “I’ve been to the hospital several times, with infections and blockages and that kind of stuff.” Yet, over time she had become used to the device and felt it could become part of a ‘normal’ routine: “I don’t even notice my bag, I have leaks occasionally, but I deal with it. I’m trying to do more and more things, um, getting my confidence back and getting my old life back.” These two examples show efforts to maintain or restore some sense of continuity from before cancer.

It was seen as sometimes useful to employ patient or survivor identifiers, but only as practical identities befitting particular circumstances (e.g., at support groups or fundraisers, with other younger patients, etc.). Mandy, who was living with Hodgkin’s lymphoma in her thirties, described these situational selves most clearly:

I would say sometimes I feel like I have the need to be a survivor and then other days I don’t want to be. You know, I don’t want anything to do with it. I just want to be normal like everyone else. You know, and then there’s, and then—most of the time probably I’m somewhere in between, you know. It’s a bit of a struggle between, you know, I want to be, but I don’t know. Like I want to be able to incorporate that into my identity in a way, but still maintain some sense of normalcy, if that makes any sense.

Hers was a common challenge among the interviewees: wanting times of integration into their local social worlds while also allowing times to see themselves (and be seen) as different.

¹³ The young adults seemed to suggest that throughout their cancer experiences some identities held fast and some faded away; to talk of total continuity or total discontinuity would be to oversimplify just how complicated, tentative, and partial their narrative identities appeared. This is why it can be more appropriate to ground their identities in transient moments of being and non-being instead of unified, enduring narrative selves. Here I am *highlighting* expressions of continuity, not *essentializing* them.

Besides a “need to be connected to that world” of survivorship, as Mandy said, people also could not always escape from that world when they wanted to. Mandy added: “I feel closer to it when I have to go for CTs or, you know, I’m at the, I’m at the oncologist’s office or if I’m having like, if I’m having any health problems... They aren’t always positive ways of relating to it.” These moments of being a survivor took Mandy and others out of their ‘normal’ lives when it became important to reconnect with cancer-related identities.

Thus, we see a dialogue between two consummated identities; on the one hand are ‘preserved’ and ‘normal’ identities from the past and on the other are ‘new’ identities from having gone through cancer. The majority of participants talked about the latter as a “*new normal*,” a concept drawn upon more and more in discourses around cancer survivorship (see e.g., Katz, 2011). ‘Normal’ and ‘new normal’ were not used as mutually exclusive or opposite notions but rather as situational identities; like Mandy, a lot of people used both to refer to specific post-treatment experiences. A new normal indicated that cancer had irreversibly changed them and it had become, as breast cancer survivor Beth described, “hard to unweave cancer from life.”

For the most part the new normal was constructed as a redirected life course, sometimes intersecting with the ‘old’ normal but never quite parallel to it. Living with a new normal was seen almost as an alternative lifestyle or unconventional mode of being, and was frequently asked to be respected as equal in value. People talked about perceiving young adulthood in some atypical ways, having different expectations and desires, and not being as committed to cultural norms of young adulthood.

Among traditional milestones, orientation toward a strong career was among the most rejected cultural ideals—often forsaken in favour of increased attention on more familial selves

(e.g., paying more attention to kids, finding or maintaining spouses, etc.). For example, Lorena admitted to being a “workaholic” before getting lung cancer, and she said she no longer coveted career advancement to the same degree she had before:

Definitely [now] spending time with the people I care about is really important to me and I make that time now, kind of no matter what. Versus before it was like, ‘Oh, well, I’m really tired’ or ‘Oh man, I’m so busy,’ and now it’s just like, ‘Ah, you know what, the work will be there when I get home.’ So, it’s that, I have more time for myself and really, like I said, it’s more about what makes me happy and fulfilled versus what other people perceive as fulfillment.

These shifts of desire marked a deviation from certain discourses that places more emphasis on work and financial identities. Thinking back to pre-cancer identities, most participants made (positive or negative) reference to identities related to labour and income, including the importance of having financial security, possessing a home of one’s own, etc. What seems to be at stake here is redefining what it means to be ‘generative’; Lorena challenged a *homo economicus* model of generativity, wherein accumulation of money and property ownership are considered markers of productivity.

The majority of young adults seemed to side with Lorena, only valuing money to the extent of paying bills incurred during treatment or preparing financially in the event of a relapse. Perhaps such rejections of work and financial selves come from an emerging disillusionment with capitalism among the ill and disabled (e.g., Oliver, 1989, 1999). Perhaps they come on the wings of economic recession, where it is relatively harder to achieve financial stability today than for the last few generations (e.g., Carrick, 2013; Coates, 2012; Henig, 2010; Lunau, 2012). This may sound counterintuitive but in their narratives, when the young adults’ ideals got too far out of reach, many of them began to reevaluate whether the goal was worthwhile.

Lorena is an excellent case in point, as she went on to assert other marked deviations from traditional milestones of adulthood. She said:

L: I no longer subscribe to the mentality of I need to meet societal norms in order to have a fulfilled life...like the whole, um, you know, buying a house and getting married and having like the 2.5 kids...

C: (laughs) 2.5.

L: ...and the picket fence, like that whole ideology.

She questioned the necessity to her sense of self-worth of marrying her current spouse, having children, or buying a house. To be sure, her experiences with cancer possibly foreclosed some of these milestones; her chemo inhibited fetal development and she could not qualify for house insurance with a pre-existing condition. Thus, some social spaces and horizons no longer inhabited the geography of her experience. Nevertheless, whether a retrospective response or a predisposition, she interpreted the closing of these life paths as of little relevance to her “fulfillment.”

We see in these ‘new normal’ moments of being a critical edge to the narratives, revealing and often challenging dominant assumptions about young adult life. The young adults rarely talked about their new normal as strictly a ‘deficit,’ a failure, or an *abnormal* way of living (these sentiments were more prevalent during the narrative sequences of separation and struggle); rather, the new normal seemed as though both a burden and a blessing at the same time, with difficult but also meaningful praxis. Some innuendos even opened it up as a more enlightened or mature experience of the world, thus, in a tricksterly way, reversing discourses about cancer as a barrier to development. After Martha pointed out what she saw as the banality of her friends’ lives, she observed:

I condensed basically into 2 years a lifetime of experiences of like getting sick, addressing your own mortality, coming back. Um, so in some ways, like, my development has been very arrested, but in other ways, sort of like emotional maturity, ability to connect, um, uh, coping mechanisms, things like that, I am much closer to people in their mid-60s...in some ways I’m sort of like even farther behind in that sort of young adult normal process, but in some ways I’m like light years ahead.

Martha seemed to qualify, or perhaps even reverse, her earlier claims about having “no growth” while living with cancer. Her words serve as a challenge to narratives of decline during young adult cancer. Playing both the part of a trickster and a phoenix, she repositioned perceived failures as life lessons by describing the “emotional maturity” she believed she gained from her experiences. Many of the participants called out cultural myths about young adulthood; while in some cases they were refitted into the new normal (e.g., choosing adoption to preserve parenthood identities when no longer fertile) in other cases the new normal was asserted as a kind of ideal itself (e.g., in Martha’s case, a fast-tracked education in dealing with life disruptions). However closely they identified with traditional milestones of development, the participants engaged in critical and negotiative work in coming to their current identities.

A third set of developmental identities emerged in this narrative sequence, perhaps best understood as unconsummated moments of non-being caught in perpetual liminality. The young adults provided a number of reasons for continued liminality in post-treatment: being weighed down by late or long-term complications with bodies and body-images, being fraught with the emotions they put aside during treatment, lacking social support or recognition, and waiting to pass the 3- or 5-year goal post. Thus, even in post-treatment time they were still quite involved in the management and surveillance of their diseases. Their desires for ‘normality’—the old or new normals—were thrust into the future as hopes or surrendered as unlikely prospects.

Many people talked of still being in transition, living with uncertainty, and not knowing how to see themselves, which broke up the repetitive rhythms of narrative identity into cacophony. Most of the time non-being was construed unfavourably; people talked about the lives they wanted now being deferred into the distant future or foregone to the accelerating past. They saw themselves as “not living,” still “recovering,” still “struggling with emotions,”

watching opportunities “dwindling,” seeing “nothing” happen after treatment and not sure what to do, facing questions of “what happens next,” “second guessing” their decisions, holding their breath that they “may die.” They often hoped for normality or new normality, wishing for a meaningful routine.

On the other hand, ongoing liminality was sometimes perceived as liberating from oppressive routines and social structures, in the way phoenix or trickster identities claim to transcend or escape suffering. People talked about being “carefree,” no longer “conforming” to others’ demands about how to be, having “no vision” of the future, being resigned to the unpredictability of life. Others simply stated they were still in a mode of reevaluating themselves and their priorities. The oldest of the interviewees, Johnny, had come to see stability as futile and he basked in the freeing potential of the unexpected. His motto was, “life is what happens when you’re busy making plans.” With a love for the ironic, he referred to his own personal philosophy as a trite platitude but one with significant resonance in his life. He told of getting unexpectedly involved in the life and death of a much younger boy with terminal leukemia:

I was trying to get my life back together, get a job again, and [David] came into my life. Hit me again. Busy making plans and life happened again. Thank Christ. I’m not religious but uh, I just hope that keeps going on with me—that life keeps happening while I’m busy making plans. And other bumper stickers.

Johnny welcomed these serendipitous moments that demanded him to become lovingly involved in the lives of others in crisis. He seemed to suggest that ‘life’ is not ‘planned,’ it ‘happens’ to a person without their intention or volition.

For Johnny and a notable minority of young adults, stasis and normality were seen as expectations placed on them by people naïve about cancer and uncomfortable with serious illness and death. For example, Penny said that while she personally felt in a liminal space, her local social world did not validate or permit it:

P: I never had chemo and I never had radiation, uh, so I think that was my downfall just because everyone just sees, oh, you don't need this and so, um, they just expect you to go back to normal. But, you're not.

C: Who, who is 'they'?

P: Um, everyone in society, like, all your friends and family and everything, they just expect, "Oh, your cancer's gone, you're clear, um, you know, you can go back to the old thing."

This point is relevant to the theorization of liminality, often conceived as a socially sanctioned or ritualized experience of uncertain statuses and identities (e.g., Turner, 1966); such is often the case with moratoria in young adulthood (Henig, 2010; Marcia, 1973) and with cancer experiences (e.g., Little et al., 1998; Thompson, 2007). Consummation is traditionally considered to be the end point of liminality, entailing the integration back into society, and we may see this when participants talked about returning to their former selves.

By contrast, many participants felt their struggles and searches became deviant, even illegitimate, after treatments finished. It is as though there are certain social markers of the expected end of liminality, an expiry date as it were, in this case, no longer being strongly affiliated with a care centre and no longer exhibiting observable 'signs' of illness. This may go for Penny and others whose sense of liminality continued beyond treatment, as well as for those who talked about the new normal—which often required the support of other cancer patients in lieu of validation from friends and family. Lack of recognition seemed to frustrate both more distressing and more therapeutic moments of non-being. During these times, liminality and the new normal were reconfigured as social transgressions, violating dominant values and expectations that cancer is a disease of the aging and even if it appears in the young, modern medicine will make it temporary. It seems that in these contexts the expected narrative sequence

of consummation can sometimes be a pawn to the imperative of narrative coherence, placing normative demands upon people who may or may not return from liminal spaces.

Conclusion: Rethinking Generativity and Development

The matter of unsanctioned liminality in cancer, along with the critical engagement with traditional milestones, seems to point to another issue at stake, what is often defined in developmental psychology as “generativity” (e.g., Baddeley and Singer, 2007; Erikson, 1968; McAdams, 2006). According to McAdams (2006), in order to be generative in a narrative context one must “salvage a good self from the past” and “integrate the person into a productive and caring social niche for the future” (p. 233). This working definition may seem reasonable, but in his language of recovery (“salvage”) and order (“integrate”) he seems to show little appreciation for the productive power of non-being, which may be potentially healing assertions of elusive selves or of the folly of socially defined paths of productivity.

Indeed, McAdams (2006) associates chaotic or “contaminated” narratives—which may contain tricksterly or tragic figures—with “lower generativity” and defines them as the opposite of redemption (p. 211-216). In keeping with his ideas about self-authorship, he suggested that the mottos of people with “low generativity” are often “living for the moment” or “going with the flow” (McAdams, 2006, p. 218), that is, people who externalize agency, speak of contingency and serendipity, or see the future as a rather bold assumption. I hope to have demonstrated that moments of non-being can be ‘productive’ in their own right, especially as deconstructions of normative expectations of the life course and as escapes from entrapping social niches. The young adults in this study put into question discourses of generativity that emphasize independence, sexual reproduction, marriage, and stable employment, and that remain silent

about more reflective journeys of development, such as life review and meditation on death (often assumed to be issues of the aging).

Given these critical responses to how young adulthood is typically conceived, we may need to broaden our understanding of what it means to be generative. Interestingly, pioneering developmental psychologist Erik Erikson (1980) offered a way into thinking about the concept in new ways. He described generativity simply as “primarily the interest in establishing and guiding the next generation” (p. 103), but went on to write that “there are people who, from misfortune or because of special and genuine gifts in other directions, do not apply this drive to offspring but to other forms of altruistic concern and of creativity, which may absorb their kind of parental responsibility” (p. 103). It seems to me that within this qualifying statement Erikson acknowledged a wide range of generative praxes, including any creative expression that in some way “guides” others.

Randall and McKim (2008) expanded on Erikson’s notion of generativity, using earthly metaphors to define generativity as “the need...to harvest the wisdom that has been silently amassing inside us across the years, and...to mix it in with the soil of the world, for the benefit of others’ growth as well” (p. 276). Randall and McKim included in this wisdom “the peculiar collection of questions and wonderings, of untold stories and thus unlived lives that constitute our particular existence” (p. 276). From my understanding, this invites the infusion of existential quandaries and biographical disruptions into the “soil of the world,” enriching it not only with normative solutions to life’s problems but also with a plethora of uncertainties. Instead of a threat to cultural ideals, expressions of liminality, non-being, and the new normal may serve as fodder for changing the composition of discourses about young adulthood and, in turn, the spaces of experience and horizons of expectation for future generations. Such an image of generativity

may enable young adults with cancer to see themselves as thriving regardless of their ‘achievements’ of cultural ideals.

There appears to be an easy parallel between this inclusive definition of generativity and Barbara Rogoff’s (2003) definition of development as “changing participation in sociocultural activities” (p. 50). In sum, they invite us to think about these matters in terms of social ‘engagement’ or, in the language of my dissertation, ‘negotiation’ and ‘performance.’ Instead of some pre-defined endpoint, like consummated or orderly identities, independent authorship of one’s life, robust careers and estates, etc., generativity may be defined by people’s participation in co-shaping the worlds of thought and action within which they live.

Development, in turn, may be understood as the product of negotiations, resulting in transformations of personal and social life. As philosopher Jean-Paul Sartre (1960/1968) argued, people “make their history on the basis of real, prior conditions” like dominant discourses, “but the movement of human *praxis*” including performances of narrative “goes beyond [their conditions] while conserving them” (p. 87; original text). For example, the young adults discussed in this chapter sometimes endorsed deficit models of development, expressing moments of feeling ‘behind’ and of feeling ‘ahead’ of their peers. While operating under these discourses, they also created avenues for thinking differently about illness and development, as alternative lifestyles, “new” and yet “normal” ways of living. It is through these negotiations of being and their social effects that, according to existentialist scholar Stuart Charne (1984), “individual human development is thus related to the development of history” (p. 4).

Narratives may be seen as a form of engagement, as sociocultural activities that make sense for oneself and for “guiding” others. They may be seen as generative in the sense of being ‘participants’ in the forming and reforming of discourses about young adulthood and chronic

illness. In their critical negotiations, the young adults' stories articulated ways of (non)being that are often unnoticed or marginalized within their narrative environments. Thinking of narratives, Paul Ricoeur (1984) said, "we owe a large part of the enlarging of our horizon of existence to poetic works" (p. 80); indeed, young adults' narratives about unconventional being and the new normal widened the range of possible lives for themselves and for those willing to listen. Their generativity is represented by the meanings and ways of (non)being they projected into public discourses, appropriating and reworking them and, in turn, potentially changing the courses of their evolution.

Chapter Conclusion: Young Adults' Manifold Identities

The young adults' narratives expressed a wide range of identities tied to mythic conceptions of illness and young adulthood. They talked often about being resilient, self-authoring their lives, and taking charge of their healing and post-treatment adjustments. However, they also spoke of the authoring power of other persons: as external pressures to be a certain way, as supports for mediating disruption, as collaborators in constructing meaningful lives. They included other forces as agents of change as well, most obviously cancer as a transformative experience, fortunate social and material circumstances (e.g., having family support and/or wealth) that eased the burdens of illness, and less explainable moments of serendipity or miracle (e.g., acts of God, fate, or randomness). While these different co-authors sometimes helped put the "narrative wreckage" of "selves-in-crisis" back together again, at other times they resisted reconstruction in ways people found despairing, frustrating, or refreshing.

Within the narratives were plenty of co-occurrences of normality and new normality, and of liminal and consummated selves. Because of their back-and-forth movement, it does not seem to make sense to identify a linear progression into stable, independent selves as registers for

development. Without necessarily ‘achieving’ tasks that some dominant discourses pitch as essential for young adults, they told of identities we could conceive as ‘developing’ in their changing participation in cultural activities.

The young adults negotiated cultural myths in a wide range of ways, producing practical identities in response to needs, desires, and available ways of being. While it is helpful to conceive of what they were doing as praxis—performing narratives toward meaningful ends—it does not follow that this was a unifying activity that created a single narrative identity. Mythic identities did not always serve the function of integrating experiences or asserting agency; some, in fact, accentuated the liminality of cancer and the fragility of selfhood during and after cancer treatment. Instead of looking for grand markers of self-understanding and development we should look to the sophisticated symbolism of mythic identities and their many uses in producing moments of being and non-being.

Moments of Meaning and Questions of Morality

What crime, what sin, had those young hearts conceived,
That lie, bleeding and torn, on mother's breast?
Did fallen Lisbon deeper drink of vice
Than London, Paris, or sunlit Madrid?
In these men dance; at Lisbon yawns the abyss.

...
What is the verdict of the vastest mind?
Silence: the book of fate is closed to us.
Man is a stranger to his own research;
He knows not whence he comes, nor whither goes.

—Voltaire, “An examination of the axiom ‘All is well’”

Introduction

In 1755, the devoutly Roman Catholic city of Lisbon, Portugal, was utterly demolished by a severe earthquake, a subsequent tsunami, and fires spreading across the rubble. This single, brutal event promulgated widespread doubts about and criticisms toward the prevailing theodicy of the times, the Leibnizian doctrine that “this is the best of all possible worlds,” that the world is justly and divinely ordered. Among the most vocal critics was Voltaire, a poet, playwright, and philosopher at the centre of Europe’s Enlightenment who vehemently opposed theological explanations of suffering. The above poem (1756/1912) used the earthquake at Lisbon to challenge moralistic assumptions that only the pious are rewarded and only the corrupt are punished. By contrast, Voltaire asserted that questions about where suffering comes from and how to avoid or alleviate it are unresolvable mysteries that are “closed” to us, and so we must forsake efforts to compartmentalize our pains into a moral order.

The kinds of moral explanations that Voltaire reacted against 250 years ago are still with us in modernity. Often expressed as the popular adage “everything happens for a reason,” these

theodicies propose that no suffering is without purpose. Anthropologist Gay Becker (1997) witness this ideology of “rational determinism” (p. 110) in her study of “disrupted lives,” including, among others, people who were living with chronic illness. She saw these interpretations as attempts to restore a sense of meaning to chaotic situations. In this chapter, we will look at this and other moralized images of suffering.

Like the surviving inhabitants of demolished Lisbon after the earthquake, and the rest of Christian Europe watching, having a chronic illness can rattle and shake even the most solidified assumptions about life, demanding people to rethink their views of reality. Psychiatric anthropologist Arthur Kleinman (1988) wrote that, “Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice—value questions, all—in the human condition” (p. 20). In sum, disruption to moral understandings can be an existential challenge to people in crisis, weakening their structures of meaning and sense of direction in life.

It is a matter of dispute the extent to which people make moral claims about the shaky ground upon which they find themselves. Some theorists of narrative suggest that simply by making meaning of experience, people are making morality. For instance, historian Hayden White (1981) argued that storying life is driven by a desire to “moralize reality” (p. 14), and that narratives participate in a “discourse of the imaginary” distinct from a “discourse of the real” (p. 19). Similarly, but in a less critical tone, Arthur Kleinman (1988) wrote that having cancer ignites “our *need* to make moral sense of ‘Why me?’” (p. 20; my emphasis), which can be answered through a therapeutic process he called “remoralization” (p. 245). Within these camps of understanding, morality is threaded into the fabric of meaning; in other words, moments of meaning are seen as, by necessity, moments of morality.

I am not sure I would collapse the two concepts, for fear that I may begin to prescribe moral explanations of illness without warrant. I would agree that morality is often at issue in making sense of illness but is not inherent to it. Anthropologist Jarrett Zigon (2008) was doubtful that “all narratives take a moral stance,” and seeing “competing and contested moral perspectives” in stories he suggested that narratives are more like “public debate[s] on local moral issues” (p. 147). Similarly, social worker Lars-Christer Hyden (1995) stated, “The question of *whether* to accept moral responsibility for one’s illness seems to be central to most conceptions of illness” (p. 69-70; my emphasis). Note that it is the “questions” and “debates,” not the concluding answers or moral positions, that may characterize stories of illness. Like Voltaire in his poem, some people attend more to “life’s fundamental contingency” and the “unmaking” of moral order (see e.g., Frank, 1995, p. 102-103), usually highlighted in journey, mystery, and chaos narratives. Such moments of meaning are often critical of or quiet about highly moralized depictions of illness, thereby indicating, “a moral interpretation is just one aspect of most everyday talk” (Zigon, 2008, p. 119).

Within this chapter I study how and to what extent the young adults emplotted their cancers along moral histories and ethical imperatives. I discuss, first, a range of dominant cultural discourses about morality in relation to illness, described by cultural psychologist Richard Shweder (1997) as “causal ontologies.” Second, I review different moments of meaning along what I saw as “moral quests” (Hyden, 1995) within the young adults’ narratives, including their use of causal ontologies. Finally, I consider the difficulties of serving as “witness” (Frank, 1995) to the contentious moral claims and challenges posed by cancer patients. Throughout the chapter I interrogate whether remoralization is inherent to the young adults’ stories of illness, which may be seen as under the ideology of young adulthood in its pursuit of moral order

(narrative coherence) and personal responsibility (self-authorship). In conclusion, I consider how we may best respond to moral accounts of cancer as health researchers: what ethical practices, if any, should be our guiding star?

Moral Experiences, Moral Quests, and Causal Ontologies

In everyday being-in-the-world people often encounter, dispute, and live out certain values; they have what Arthur Kleinman (2006) called “*moral experiences*.” This is how he defined them: “Just carrying on our existence, negotiating important relations with others, doing work that means something to us, and living in some particular local place where others are also passionately engaged in these same existential activities” (p. 2). In other words, part of our being-in-the-world is applying our moral compasses to everyday actions. In liminal spaces, such as during a disruptive illness, moral experiences may have to be reevaluated as a new set of questions, dilemmas, and choices may arise.

As people who are ill narrate their existential challenges, they may initiate what could be called “*moral quests*” (Hyden, 1995), stories in which their values and ethics are disrupted and reevaluated. I use a journey metaphor deliberately, as their explorations are most often expressed as moments of sojourning (though they may also be at the same time moments of fighting, inspecting, healing, etc.). These quests may emplot past and present in terms of “moral lives,” defined by Kleinman (2006) as ideal futures formed out of people’s sense of right and wrong (p. 2). Moral lives are those that people imagine or desire for themselves, the lives that “[embody their] own moral commitments” (p. 2). However, contrary to some of the journeys images I discussed in chapter 4, moral quests may never end, unfolding in an iterative process of reflection, exploration, and commitment.

Moral concerns in illness narratives are often regarding the causes and effects of a given event. Causality, in everyday stories of health and illness, is related to assessments of normality, responsibility or blame, and future control or predictability (Shweder, 1997, p. 123). Narratives of suffering often interact with what may be called “*causal ontologies*” (Shweder, 1997) or “explanatory models” (Kleinman, 1988), cultural discourses that reconstruct personal suffering within a larger, moral order of predictable events. Causal ontologies are affirmations of a certain reality in order to explain peoples’ presents in terms of their pasts (i.e., give etiological models) and identify ethical directives for proceeding into ideal futures (i.e., provide reconciliatory models). In other words, they provide spaces of moral experiences and horizons of moral lives that inform people’s moral quests. Within these ontologies are proposed ‘lessons’ of suffering that offer “responses to urgent life circumstances” and “justifications for practical action” (Kleinman, 1988, p. 121).

I use these different concepts—moral experiences, moral quests, and causal ontologies—to study how the young adults interacted with larger moral orders as they faced myriad existential challenges. See Figure J1 for a representation of these concepts within my theoretical framework (Appendix J). Throughout the following section, I explore the interactions between dominant causal ontologies, personal moral experiences, and moral quests as the young adults made sense of their pasts, presents, and futures.

Moral Quests: Making and Unmaking Moments of Morality

Dominant Causal Ontologies

People may interpret their illnesses in a wide variety of ways, and they may do so by drawing upon cultural explanations of the origins and effects of disease. Any number of these causal ontologies may be constructed around illness. Shweder (1997) outlined seven notable

varieties—astrophysical, biomedical, socio-political, environmental-stressful, interpersonal, psychological, and moral (p. 119-123)—that may be part of the narrative environments available to the young adults I interviewed. Below I reconfigure these ontologies in relation to the young adults’ narratives, as well as put them into historical contexts. See Figure J2 for the hierarchical dominance of the different causal ontologies within the young adults’ narratives¹.

Astrophysical explanations are perhaps not as well-known, but at least from the ancient Egyptians to modern astrologists the arrangements of cosmic entities have been analyzed to see how they may be related to the fortunes and misfortunes of people on Earth. Their unfamiliarity is reaffirmed by their absence within the young adults’ stories. It seems that despite the omnipresence of horoscopes in many daily newspapers, despite one of the Zodiac signs being *cancer* (the Latin word for “crab”), and despite “medical astronomy” having a small following of respected practitioners into the 20th century (Harrison, 2000), astrophysical discourses have not leaked into mainstream, contemporary conceptions of cancer.

The closest expressions of a cosmic ontology within the young adult narratives would be in reference to fate or divinity (oddly, not singled out in Shweder’s causal ontologies). “Rational determinism” (Becker, 1997, p. 110) was relatively common with assertions that cancer “happens for a reason”; much less common but still somewhat present were references to “God’s will.” These claims share with astrophysical explanations a concept of destiny or of cosmic logos and they often imply an agentic mover of the universe who intends to inflict illness, for whatever reason.

Most familiar to the world of cancer care is a *biomedical* ontology of cells, bodily fluids, organic processes and so on. All of my participants employed a biomedical vernacular at some

¹ This hierarchy was developed in a parallel way to the hierarchy of moments of meaning in chapter 4, namely, by studying the frequency and overall significance of these moral meanings within the narratives.

point in their narratives, discussing cell toxicity, biomedical diagnostic labels (e.g., “acute lymphoblastic leukemia,” “anaplastic astrocytoma,” etc.), “biopsies,” “CT scans,” “stem cell transplants,” chemotherapy drugs (e.g., “doxorubicin,” “cisplatin,” etc.), and other procedures used and justified within the contexts of medical oncology.

As obvious and natural as these descriptors may be to the average cancer patient, they are neither universal nor ahistorical; according to cultural critic and teratoma patient Jackie Stacey (1997), they emerged out of the “medical patriarchy” of the last three centuries, during which time cultural notions of causation and responsibility shifted radically (p. 207-208). While prior ontologies associated suffering with divine punishment for moral failures (p. 229), dominant discourses moved toward more ‘naturalistic’ explanations. They also endowed medical experts with both the power and responsibility to heal, moving the attention away from patient-divinity relationships and toward healer-disease relationships (p. 224).

More *interpersonal* ontologies of suffering usually interpret illness through relationships of abuse and hostility, cross-culturally encompassing everything from harassment and online bullying to sorcery and curses (Shweder, 1997, p. 126-127). Having more ‘microsocial’ foci, including intimate relationships between friends, families, or lovers, these discourses suggest that malicious intent and abusive treatment may maim, afflict, or kill another person. A few of my participants talked about the influence of bad relationships in the development of their illnesses; often these were seen as exacerbating factors, making it more difficult to cope with or recover from cancer. Only a couple people suggested more direct interpersonal impacts, including spouses or bosses who “made cancer grow” by heightening their distress. Interpersonal ontologies paled in comparison to the use of biomedical ontologies within the young adults’ stories.

Socio-political ontologies often trace illness to more ‘macrosocial’ matters of oppression, domination, and other adverse social conditions. In modernity, these discourses may be loosely associated with the patient empowerment movement that began in the 1970s, in which among other demands there was a collective call for medicine to broaden its scope (Stacey, p. 208-209). Physicians were criticized for treating symptoms in individuals but not the presumed larger social causes; medicine was often seen as making a dehumanizing separation of disease from its ties to personal suffering, political oppression, and power imbalances in the doctor-patient relationship (Stacey, p. 208-209). Yet, these origin stories are almost entirely absent in the sample of young adults, with a couple of exceptions; however, as discussed in the two previous chapters, issues of empowerment, self-advocacy, and political conflict tended to arise more frequently when patients and care providers did not see eye to eye. Similar to interpersonal explanations, these were typically narrated as exacerbating, not originary, factors.

Discourses of “*environmental stress*” seem to share interest in macrosocial issues, suggesting illnesses are external afflictions from one’s physical and social atmosphere, including traffic noise, light and car pollution, busy lifestyles, radio waves, etc. (Shweder, 1997, p. 123; Stacey, 1997, p. 127). These discourses have emerged quite recently, as criticisms of the supposed “evils of modernity” (Shweder, p. 217), such as capitalist exploitation, industrial pollution, excessive consumption, and so on. Interestingly, there are many more moments of environmental-stressful explanations than of socio-political explanations, drawing more attention to adjusting personal “lifestyles,” reducing “work” stresses, balancing “yin” with “yang” or tranquility with busyness, eating “organic” and following a strict “diet,” and maintaining overall “physical health.”

Psychological ontologies explore repressed or lived out desires, fears, fantasies, or emotions as the cause of illness. More than most other ontologies, these place responsibility heavily upon the person experiencing suffering (Sontag, 1978, p. 55-56). Cultural critic Susan Sontag (1978) observed that, “there is a peculiarly modern predilection for psychological explanations of disease, as of everything else” (p. 54). Thus emerged in the early 20th century cultural discourses of a “cancer personality”: someone who was said to repress his or her urges, had an apparent “inability to feel,” and was considered “one of life’s losers” (Sontag, p. 48).

The cultural associations between cancer and psyche may have waxed and waned with the prevalence of certain ideologies. Stacey (1997) wrote of the presence of psychological ontologies within “hyper-individualistic” conservative political parties that took power in 1980s Britain (and the U.S. and Canada), who defunded medical care and argued each person is responsible for his or her own illness and wellness (p. 209-211). Self-health and self-help approaches of the last few decades also tend to locate the origins of disease “within the individual,” often as an “expression of that person’s lifestyle,” a “physical manifestation of psychic distress,” rather than a “malfunction of the ‘natural’ regulation of the cell system” according to biomedicine (Stacey, p. 217).

Such discourses were produced in the young adult narratives, often interwoven into environmental-stressful ontologies. For example, “stress” was largely seen as a psychological concept among the young adults, though tied to external factors; many of the suggested changes to lifestyle included “calming” down, “thinking positively,” altering their “perspectives,” “reducing stress,” etc. Not necessarily references to cancer personalities, they implied that thinking and feeling a certain way enhanced the probability of cancer and, by extension, death.

Shweder (1997) wrote of a seventh set of *moral* ontologies that locate suffering within moral transgressions or failures to uphold some obligation or ethical duty (p. 127). I appreciate that there may be nuanced differences between moral and other ontologies, but the former does not seem to stand on its own. Moral ontologies seem implicit in all the others: an interpersonal ontology in cases of transgressions, a socio-political ontology in circumstances of human rights violations, a psychological ontology in situations of personal responsibility, and so on. They all seem to propose moral imperatives and ethical practices, whether of reconciliation, environmental movements, societal revolutions, or lifestyle changes.

Shweder admitted as much when he concluded that, in the world of lived experiences, no causal ontology is an isolated silo (p. 140). Like narrative genres, these causal ontologies are not mutually exclusive and in an individual narrative may bring several into dialogue². For instance, anthropologist Linda Hunt (1998) found 48 moments of moral explanations (including emotions, sexual activities, lifestyle, environment, heritage, etc.) within the narratives of 25 Mexican women with either breast or cervical cancer—showing that often more than one cause is suggested. Causal ontologies are often intermixed, negotiated or challenged, rendering explanatory models of illness that are intricately complex and not always morally relevant. There were also moments of resisting causal ontologies, what we could call amoral or *absurdist*³ positions on suffering. Many of the young adults were at one time uncertain about how to

² That said, causal ontologies may be unequally distributed across the globe (Shweder, 1997, p. 120-123); for example, illness tends to be diagnosed in Western nations as a disease of biological and ‘natural’ origins, while in many traditional tribes in Africa sorcery and spirit attack are much more familiar explanations (p. 122-123).

³ I am not sure the term ‘amoral’ is the best way to talk about resistance to causal ontologies. To say illness is amoral, for instance, is that not a moral way of talking, in so far as one is saying ‘this is the state of the world’? Furthermore, notions of “chance” and “randomness” and “chaos” that follow from allegedly amoral accounts are themselves cultural categories, not without historical origins. I prefer to link these metaphors with ‘absurdist’ beliefs in the “benign indifference of the universe” (Camus, 1942/1946, p. 76) to human affairs, shared by not only Voltaire in his criticism of Leibnizian theodicy, but also many modern existentialist philosophers, natural scientists, medical professionals, and atheists in response to religious explanations of suffering. Statements about the amorality of cancer may, in fact, be a cultural expression of certain secularized traditions or *mores* (which is the etymological root of “moral”) regarding a capricious world.

explain their cancers; they said they had “no clue” about its origins, it could be a “potpourri of things,” “maybe in the environment, technology, or our food.” Sometimes they said that their cancers were an indeterminate “mystery,” and that perhaps there was “no reason” or “no final answers.”

Moments of negotiating and resisting ontologies show that a singular moral order may not always be sought. Producing multiple causal stories may, quite the contrary, be essential to understanding illness experiences and directing actions. Narrative psychologist Mark Freeman (2010b) wrote that, “causation in history is a plural matter...a given outcome is often ‘overdetermined’” (p. 40). Shweder persuasively argued that “it is often advantageous to have more than one discourse for interpreting a situation or solving a problem” and this may be “the most effective method to meet the vicissitudes of human ethical experience” (p. 140-141). As we will see below, the young adults’ causal ontologies were often overdetermined, expressed as several possible (and rejected) answers to where cancer may come from and how in spite of it one may lead a moral life.

Moral Meanings as Quests: The Cases of Jeanine and George

Creating meaning of suffering is often seen as a cross-cultural, perhaps even universal phenomenon. Richard Shweder (1997) proposed that “wherever one looks on the globe it appears that human beings want to be edified by their miseries” and have a “desire to make suffering intelligible” (p. 119). But, can we presume that edification and intelligibility are always pursued and desired? I have made the case against this presupposition in the previous two chapters; in particular, I wrote of moments of disordering as well as moments of non-being that sometimes provide release from overburdening or unconvincing cancer discourses. I proposed that these moments are commonplace across my participants’ narratives, and not just a characteristic of a

particular *kind* of story (e.g., a chaotic narrative). I concluded that these moments communicate the on-going instability of meaning and being within illness narratives, the *chronic* possibility of disruption and disorder in the lives of young adults with cancer.

It may be that orderly moments of meaning and being are more so horizons of expectation than universal truths about storying illness (see e.g., Rimmon-Kenan, 2002). It may be that, contrary to what they want to say, many people who are ill are compelled to tell coherent stories, present restored selves, and provide moral lessons. A common trope around chronically and terminally ill people is that they are beacons of moral education. For instance, Dr. Morrie Schwartz, the famed sociologist who became the dying sage and protagonist in *Tuesdays with Morrie* (1997) and a series of television interviews for ABC's *Nightline*, has become the exemplary image of the instructive patient. Imparting moral wisdom about life and death seemed to come easy for Dr. Schwartz, neatly packaged in pithy aphorisms and informative parables.

But, he was quite aware that he had an audience and often seemed to tell his story in a way that appeared satisfying and digestible to them; in the book written about him, he was quoted as saying, "I'm on the last great journey here - and *people want me to tell them what to pack*" (p. 33; my emphasis). Not everybody who encounters chronic or terminal illness takes on the confident didactic role that befitted the retired professor, and it may be that he was inhibited by dominant expectations to tell less inspiring or less orderly narratives of dying. Voices expressing struggle or ambiguity around moral issues are often eclipsed by such dominant images as presented by Dr. Schwartz.

I wanted to avoid reifying the young adults as sages of moral wisdom, by attending to their doubts and queries along with their assertions of moral meanings. In order to do this, I re-plotted their stories as moral quests, that is, expeditions into and sometimes away from moral sense. I

divided their quests into three different, non-sequential moments of meaning: a) moments of existential questioning when taken-for-granted assumptions were shaken to their core; b) moments of moral explorations when the young adults engaged and negotiated different explanations of cancer; and c) moments of moral living when they considered the directions of their future in light of their understandings of the past and present. I expand in turn on each of these moments of meaning within the young adults' stories. I delve further into the complexity of these explorations by drawing on two exemplary narratives, in their self-reflexivity revealing most effectively the diverse and complex moral quests that the vast majority of participants also traversed. Let me first introduce them before entering into their moral quests.

Jeanine

When I met Jeanine, she was in her late twenties, three years post-treatment, and suffering inexplicable abdominal pains. Her story of becoming ill began just after having her first child with her husband, when she went in for a routine postpartum pap test. The test results came back with abnormal cells, which perplexed her and her gynecologist. The results of a biopsy came in three days before Jeanine was to receive life insurance: she had cervical cancer. She was subsequently refused her insurance. Over the next several months she had appointments with oncologists and healthcare staff to get more information about her cancer.

She was initially treated with a trachelectomy, a surgical procedure in which the cervix is removed while the uterus is left. This procedure is done in order to preserve the person's fertility, in case she wished to be pregnant again. Unfortunately, it was discovered later that the cancer had spread to her lymphnodes and she would require 5 weeks of chemotherapy and radiation therapy. All of this rendered the trachelectomy unnecessary as Jeanine became infertile from the other therapies. In fact, her surgery created more complications than it solved, as it brought her

enduring pain and prevented her from lifting anything heavy, including her newborn child, lest it caused internal tearing and hemorrhaging. In terms of moral challenges, she said she was struggling to make sense of her cancer's origins as well as find her place in the world around her.

George

George was in his late thirties and was three years post-treatment from his second cancer when we began our interview. He found a lump on his groin in the midst of planning his wedding. His blood tests initially came back negative, but a few months later he was diagnosed with acute lymphoblastic leukemia (after being misdiagnosed with Non-Hodgkin's lymphoma). He had three rounds of chemotherapy, with three years of maintenance treatments (i.e., lighter doses of chemo). He and his wife were married six months into his experience with cancer. He was without symptoms for seven years, but after experiencing pain and pressure in his back and head, cancer cells were found in his spine and cerebrospinal fluid. At this time, George and his wife were preparing for their second child. He was treated with three more cycles of chemotherapy, a stem cell transplant, then radiation and more chemotherapy. As a result of the cancer and its treatment, he had some reduced vision but otherwise had few late effects. George was also having trouble finding his place as he searched for moral visions to guide his actions.

A) Moments of Existential Questioning

Overview: Questioning Pasts, Presents, and Futures

Moments of existential questioning often expressed disruptions to participants' ways of living and taken-for-granted values, instigating their struggles. These were often, though not always, moments of crisis and confusion leading to what Arthur Frank (1995) saw as a "departure" from everyday life and onto journeys toward understanding (p. 117). However, the

degrees of intensity and the aspects of life permeated by doubts varied notably at different times in people's narratives.

Almost all of the people I interviewed noticeably expressed existential questions, many of which were in search of causal ontologies. They phrased questions along the past, *how did I get here?* Often these kinds of questions were framed generally, in two very simple words: "Why me?" In these moments, people spoke about not being able to "process" or "digest" their diagnosis, not being able to emplot it within their accounts of their life histories. Diagnosis radically challenged their perceptions of the past, producing what anthropologist Sarah Lochlann Jain (2007) called a "counterfactual," a former life history that does not seem to match up with the emerging story of having cancer. A common example would be believing one lived a 'healthy' life (e.g., exercising, dieting, etc.) only to find later that under the surface one was ill⁴.

At other times people asked more specific queries about whether they were being "punished," whether they were "guilty" of some transgression or crime, or whether it was the will of "God." A few people claimed there is a discrepancy between their lived experiences and discourses that promise healthy eating and frequent exercise will prevent cancer; these frustrated individuals said they "thought" they were "healthy," they "tried to be fit," and, yet, they "still got cancer" and all their "hard work was undone." During these moments of questioning, people said they had "no clue" about where their cancer came from and felt that it was possibly "purposeless," having no bearing on the (im)morality of the past. The origins of their disease seemed to be mysterious and elusive, perhaps even absurd or arbitrary.

Adrian, a brain cancer survivor in his twenties, described the difficulties in pinpointing the origin of his disease in this way: "you just got to realize, um, that these things come up and

⁴ This is also an example of how different sources may thrust individuals into "unhomelike being-in-the-world" (Svenaeus, 2000); instead of a phenomenological experience of feeling themselves getting ill, some young adults entered into unhomelike being through a social experience of being told they were ill.

unless you're in an environment where, um, like maybe a mine or something, generally you don't know why these diseases develop but you just got to deal with them as they come...[The oncologists] don't know why, they know that sometimes, um, these things happen with genetics, but that's just shooting in the dark." Even though genetics is an available way of 'tracing back' his brain tumour, he struggled to come to a satisfactory answer.

Another series of questions arose quite frequently around the present, *where am I now?* In reflecting upon their current situations—their treatments and time after treatments—people often talked about being in a “crisis” or “grey period,” “flying without a net,” with “no answers.” Some described feeling “numb,” “overwhelmed,” “demoralized,” “unsettled,” or in “disbelief,” caught in a number of “catch 22s” and confused about their “place” in the world. They seemed lost within an unhomelike present, a place of exile, alienated from where they used to be.

Finally, an array of questions sprung up from my participants with regard to the future, *where am I going?* Simply stated as “now what?” or “what’s going to happen?” these questions often articulated that there was “so much uncertainty,” “anxiety,” and “moments of panic” about the future beyond treatments. Some young adults said they “don’t know what life has in store” for them; they sometimes saw “no finite end” to their illness, suspected pains or symptoms as “signs” of “possible relapse,” and thought they “might die” from their cancers. In these moments they questioned their “expectations” about life and became convinced they were “not returning” or “going back” to “normal.” They constructed their illnesses as distant journeys away from home. The narratives of Jeanine and George relate these experiences of alienation in more personal ways to the worlds of importance to them.

1. Jeanine's Questions: Reflecting on Regrets and Suspicions

Let's look first at Jeanine, who talked about two distinct phases in her cancer experience: first, what she called the "survival" or "denial" phase, which prefaced her moral quests; and a second "reality" phase during which many existential questions started to emerge. She saw the first phase as a response to feeling overwhelmed by her unexpected diagnosis: "I felt very lost [initially]... You feel a total loss of control." She reported frantically searching for something to focus onto, a crutch to keep her balanced.

She said her sense of control was restored by developing a "plan of action" with her medical team to conquer her cancer. Her attentions honed in on getting through her treatments and little else. It may seem strange that she would talk about this period as a "denial" phase, given that the term is often used to denote a refusal to recognize the life and death gravity of a situation. However, what she claimed to have denied was not death itself, but rather the existential questions and emotional weights that awareness of mortality can bring.

Her commitment to survival was buttressed by what she saw as a moral duty to her child: "[I] told [my husband] I would do whatever it took to be here for our daughter... I didn't need more children, I just needed to be there for the one we already had." Despite survival being more at stake than the ability to bear children, her and her husband agreed to the trachelectomy because they "had always planned on having a larger family."

Three years without a recurrence, her survival phase appeared to give way to "reality" and, peculiar though it may sound, she said, "dealing with the aftermath of having cancer is a lot worse than dealing with the cancer itself." According to her, the first concern to haunt her was her treatment decisions. She says, "I question everything; I want to know why this route of treatment was chosen for me... I have regret to the decisions that I've made with my treatment."

She described “feelings of anger, regret, and bitterness” toward her choices, sometimes suggesting she was not given a fair weighing of the pros and cons of a trachelectomy over a hysterectomy. This doubt and frustration contributed to what she called the “emotional strain” of cancer. Of special difficulty was the inability to carry her child while she recovered from the surgery and its complications. She says, “not being able to lift my daughter was the hardest of anything I had to deal with. Everything with my cancer being surrounded around my maternity leave made me feel robbed of the first year of my daughter’s life.”

Jeanine also ruminated anxiously over the origins of her illness. She asked herself, “Why me? What made me get cancer over anybody else?...This is something we’ve all asked ourselves at some point, ‘What did I do to deserve this?’” She reported struggling with contradictory discourses about where young adult cancer comes from. On the one hand, she said she encountered a dominant discourse of personal responsibility for cervical cancer: “Everything I’ve been told by the research is that the choices I’ve made in my life are what led to me getting cancer.” Cervical cancer research tends to emphasize human papillomavirus (HPV) as the highest risk factor for the disease by a wide margin, with 99% of cervical cancer patients also having HPV (see e.g., Walboomers et al., 1999); HPV is considered a sexually transmitted disease and, as such, is subject to moral judgments about the sexual practices of those infected. This is an example of how biomedical rhetoric can evolve into “medico-moral” discourses (Harris, 1989) as they intermingle with other discourses, in this case, of sexual transgressions.

Jeanine was somewhat swayed by this discourse, indicating in her written narrative that, “I feel there were events that happened prior to my diagnosis that may have resulted in me getting cancer.” However, she questioned her own inclinations. In a conversation with herself, she admitted, “that is debatable, however, especially when some ‘cancer theologians’ say there is

nothing at our age we could've done to get cancer.” Who she saw as “cancer theologians” is unclear, but Jeanine was trying to sort out whether she was culpable in some way for her cancer. Some of her ideas come out in her moral explorations, which I return to in the next section.

Another contentious issue for Jeanine was her place in the world once she had recovered from her cancer. She says, “I question where I’m supposed to be and what I’m supposed to be doing with my life...feeling a bit more urgency to find answers.” Much like her initial feeling of disorientation when she was first diagnosed, she expressed being lost within her moral quests, alienated from both a meaningful present and a valuable future. This sense of loss comes back to her emotional turmoil, where she says, “I am also finding myself feeling pity for my situation at times, or rather I feel sorry for myself. I also feel like I have no control over situations.” These moments, spread throughout her narrative, communicated moral struggles oriented toward the past (i.e., why she had cancer), the present (i.e., where it had brought her), and the future (i.e., where she was “supposed” to be heading in life).

2. George’s Questions: Searching for a Place in Many Worlds

George had his own set of moral struggles, some of which paralleled Jeanine’s. During his treatment, George witnessed friends who died of their cancers while he remained. He said this is what began his existential questioning. He suffered from what is often seen as ‘survivor remorse,’ or the “culpability of the survivor” according to philosopher Emmanuel Levinas (1993/2000, p. 12); he asked not “Why did I get sick?” but “Why am I still here?”

Similar to Jeanine, he began to ask about his “place in the world *as a survivor*” (my emphasis). Life with cancer changed his relationship to the world around him, manifesting an unhomelike sense of being, and he sought out a new home. It is perhaps more accurate to refer to worlds in the plural, as George’s notion of “the world” seemed to expand and shrink throughout

his narrative. Sometimes he spoke concernedly about his *familial* world, especially his children.

He says:

I'm very conscious of the legacy I'm leaving for my kids...in the sense of like 'Who *is* my dad?' If I'm dead in two years or ten years, what are they going to remember about me? Am I going to be just another guy who just *worked* a job, you know...Or *is* there going to be something special about me? Are they going to be proud of me? (my emphasis)

George's play on past and present tense throughout this quote (see italics) shifted the temporal positioning of his story from 'now' to a possible future when he doesn't exist. This may reflect some ambiguity on George's part about whether he will be alive when his children grow up. Yet, it was not the death of the self that worried him most; his image in the eyes of his children seemed to be more at stake in his existential concerns. He wanted to build a "legacy" that his children would find worth living and would thus commemorate. As both George and Jeanine addressed their futures, what seemed to concern them most was a *generative* project, that is, locating prospective contributions they could make to the lives of their local social worlds (refer back to the previous chapter for more detail on struggles with generativity).

At other times, the social sphere of relevance to George ballooned. For instance, he wrote, "[I have a] strong desire to do what I can to make my *community* and the *world* a better place" (my emphasis). Here the "community" (vaguely identified) is a broader *local* world than family, while the "world" in this excerpt signifies an even wider, perhaps global, range of stakeholders. He wrote about feeling compelled toward contributing to all three of these worlds, wanting to find a way to juggle them in harmony. No easy task to sort out, George seemed to be understandably at a loss for how to go about performing his various commitments.

Conclusion: The Unpredictable Timing of Existential Questioning

Along the meandering and foggy roads that can be chronic illness are many encounters with doubts and uncertainties (see Figure J3 for a summary of the above existential questions).

George and Jeanine came across shared existential questions around their purposes and places within larger social worlds, especially their families. What was predominantly at stake for both of them was being there for their children and contributing to their futures, as was the case for other parents in my study. Despite this grounding intersection in their narratives, George and Jeanine shared very few other paths along their moral explorations.

We see the extent of their differences as we go through other sequences of their narratives below, but here one crucial point needs to be made: moral quests can start at various times in the lives of cancer patients. George and Jeanine told of two different catalytic events in the “departures” (Frank, 1995, p. 117) on to their moral quests. George said he started to ask himself more questions in the rooms of dying and dead friends he had met while in treatment. This was a common statement, where participants said they discovered the gravity of their own situations upon witnessing the deaths of those considered to be in comparable circumstances. Jeanine’s “survival” phase, where moral and existential issues were ‘set aside’ until the possibility of death became less imminent, was also a familiar narrative among other participants. Once treatment was finished, the threat was more distant, and people exited the routines of their medical institutions, then all that couldn’t be dealt with in the midst of treatment suddenly ruptured into an emotional crisis.

Whether due to the shock of being diagnosed at a younger age, the demanding commitments of appointments and treatments, or the unclear space of post-treatment (e.g., not knowing if a relapse is in the future), any of these encounters may lead people back to troubling moments of questioning. In any case, their moral quests did not necessarily correspond to biomedical quests of treatment and remission. George saw his beginnings in the middle of treatment, while Jeanine saw hers at the end of treatment. This can be problematic, as mentioned

in chapter 5, when medical staff and/or patients' communities assume that once treatment is finished the questioning and uncertainty *should* stop.

On the contrary, many of the young adults I interviewed expressed a sharp disconnect or sense of abandonment as soon as their treatments ceased, being thrown out into a world and left to make sense of their new liminal statuses and emerging moral questions by themselves. Their explicit criticisms of post-treatment care—not to mention several confessions within oncological research (see e.g., Ramphal et al., 2011; Paul et al., 2011)—indicate that much is lacking in practice and understanding of young adults' challenges. That said, most of the young adults seemed to find answers to their many questions, not *an* answer but *many* answers through exploring different possible realities. It is this process of moral exploration to which I now turn.

B) Moments of Moral Explorations

Overview: Provisional Endings

Moral explorations often serve as “initiations” (Frank, 1995, p. 117-118), the first steps away from existential questions and toward emplotting moral experiences within causal ontologies. Moments of moral explorations in the young adults' narratives built upon the questions *how did I get here?* and *where am I now?*, constructing possible plots of the past and present. Moral explorations often involve a “dialogical” activity of engaging with what Lars-Christer Hyden (1995) called “platforms” (p. 75) or “various possible standpoints, perspectives, and options” within people's narrative environments, in order to produce “tentative versions of the life narrative” (p. 70).

This reflective or experimental activity may be seen as a form of “subjunctivization” (Good, 1994), cultivating several possible versions of reality in order to answer existential questions around one's illness. There are various ways we may understand what is going on in

engaging different ‘platforms.’ On the one hand, they may be for the purpose of what Arthur Kleinman (1988) referred to as “remoralization,” the construction of an “illness narrative that will make sense of and give value to the experience” (p. 54). Remoralization may instill hope, understanding, and direction into a life suffering from a receding sense of coherence. In the process the suffering person is re-positioned within the frames of moral actions—mistakes and corrections, good and bad judgments, responsibilities and vindications—as well as moral agents—villains, heroes, victims, caregivers, conspirators, tricksters, etc. In sum, the process of imbuing actions with moral meanings could be a movement toward narrative coherence and assigning agency to oneself as a method toward self-authorship.

About half of my participants talked about their moral explorations in this way. They claimed they were seeking “purpose,” “redemption,” “something good,” or “a sense of clarity” about their illnesses. Some asked for “guidance” about what “lessons” to take away from their experiences, or “demanded answers” from others. Others “sought out” their own answers from “meditation,” “philosophy,” or the guidance of others, initiating a change in their “perspective,” “priorities,” sense of “hope,” etc. Finding “humour,” “gratitude,” and personal “strengths” were commonly raised as avenues toward remoralization. What seemed to be emphasized in these descriptions of moral struggle was a need for order and direction, visible paths from people’s pasts to presents in hopes of leading to desirable futures.

On the other hand, exploring different platforms may also be seen, under the rubric of a “pluralizing hermeneutics” (Marquard, 1981/1989), as an activity of producing multiple interpretations of one’s illness without defining one of them as *the* truth. Surely some realities may be preferred over others, but subjunctivization is not simply the production of a pleasing or preferable interpretation, it often entertains a variety of favourable and unfavourable

possibilities. Sometimes moral explorations may not be moving toward “sense” and “value” in the singular, but rather opening up its meanings to an array of senses and values, some in contradiction to others but all in some ways plausible. In some cases, they may be disputing or disrupting certain causal ontologies, in a sense amoralizing disease or making it appear *absurd*.

A sizable minority of young adults talked about their explorations in ways that suggest opening up or problematizing the available ways of making moral sense of their lives. These individuals talked about wanting to “take a step back,” “reevaluate” their assumptions and desires, “shift focus,” “doubt” previously held beliefs (e.g., that diet and exercise will prevent cancer), and “abandon” those that are questionable. These moments of moral exploration seemed to articulate less certainty or less desire in discovering a singular moral meaning, in a way parallel to moments of non-being discussed last chapter that resist singular narrative identities.

When I asked a young woman in her twenties, Lorena, to write about her experiences of lung cancer, she mentioned at length the “stigma” and “injustice” of dominant moral associations between lung cancer and smoking: “If I could have a dollar for everyone who’s asked if I smoked, I’d be able to take a pretty nice vacation. I realize people are curious and don’t understand how someone my age can get something like this, but it is frustrating, especially when asked by medical professionals.” Lung cancer is a particularly moralized form of cancer, as Lorena noted, and this may be partially due to the extensive media attention it has received in the past (e.g., the intentionally grotesque images of cancerous bodies on Canadian packs of cigarettes). Lorena vehemently challenged these associations: “I want people to realize that the face of lung cancer is changing. It’s not just smokers or older people, but it’s someone like me...No one deserves cancer, whether one smoked or not.” In a tricksterly way, she did not seem to offer an alternative explanation as to who gets lung cancer and why; she only pointed to the

fact that causal ontologies can unjustly imply that people ‘deserve’ their suffering. That moral origins were absent in her story suggests that remoralization may not always be a possible or desirable part of constructing illness narratives.

It may be better to interpret moral quests not as linear paths toward coherent, remoralized narratives, but rather as iterative negotiations that are fraught with difficulty and never quite completed. According to Mark Freeman (2010b), our life stories are “always provisional and revisable” (p. 85), and moral struggles may be one of many catalysts for revising and reevaluating our stories. At any point in life a new experience may (somewhat or completely) transform the meaning of an earlier one (Freeman, p. 85), possibly challenging presumed causal ontologies.

Illness narratives, in particular, often contain a “provisional ending” (Hyden, 1995, p. 72), open to more travels, adventures, doubts, and discoveries. For instance, journalist Joyce Wadler wrote a revised edition of her cancer memoir *My breast* (1994), and later contemplated writing a whole new book in response to a later diagnosis of ovarian cancer (Teucher, 2001a, p. 170-171; Teucher, personal communication, February 11, 2013). She eventually gave up this project, possibly because new changes and challenges made it quite difficult to write a *final* ending. Relapses, among other turning points in life, can convert what was initially assumed to be a concluded journey into a more indefinite affair. Stories must then be re-plotted, explorations continued, moral orders revised. Jeanine’s and George’s explorations entertained many different causal ontologies and moral responsibilities at the same time, expressing unsettled, “tentative versions” (Hyden, 1995, p. 70) of their moral understandings.

1. Jeanine's Explorations: Family Duties, Tough Decisions, and Multiple Origins

Recall that Jeanine was most concerned about her place in her social world after having cancer, the emotional turmoil she felt from the treatment path she took, and the events within her life history that may have caused her cervical cancer. In terms of her place in the world, she spoke of being self-centred before cancer and how she saw that as a kind of moral flaw. She said that before cancer “life was about me,” young adulthood was about “paving your own path,” and during such times “you think you’re invincible.” Comparing her past to present, she said that now her daughter is, “the centre of my life.” She also expressed the need to share her experiences with others, to help others going through cancer, or simply raise awareness about cervical cancer. Her explorations first communicated a new ethic of caring for others.

However, these plans, she said, “[have] been put on the back burner, and the main focus has become to first deal with my own physical and emotional health, as my third year following my diagnosis has been my hardest year so far.” Her trachelectomy caused a lot of late complications, including some ambiguous abdominal pains that neither she nor her physician could explain. As she was telling her story Jeanine said she worried, above all, about a relapse: was she going to die because she made the “wrong decisions” the first time? Her physician had suggested getting a full hysterectomy to alleviate the pain, a recommendation that she also received with suspicion. She felt she had gone “full circle” since her first treatments, as she struggled to decide on what to do and whether the medical advice she was given was the best.

Another area of contention for Jeanine was her cancer’s causal ontologies. Jeanine saw tensions between common biomedical explanations of young adult cancer and her personal reflections. At odds with dominant discourses of cervical cancer and Jeanine’s own inclinations, discourses of young adult cancer tend to promote a genetic origin story, based on the assumption

that young adults have not had enough “exposure” to “environmental” carcinogens to develop cancer (see e.g., CCS, 2006, 2009). She attended a presentation on young adult cancer and listened to the speaker repeatedly say:

There is nothing you have done at your age to deserve getting cancer”... You know, and I think he was doing it to make us feel positive and empowered and that, so I don’t disagree with what he was doing. But, I have trouble agreeing with it 100%.

Jeanine was somewhat dissatisfied with this biomedical causal ontology, though not without understanding what it serves for many patients. Jeanine did not want to dismiss these claims outright, but she said time and again she could not accept that her illness came from nowhere.

She proceeded to construct a narrative of her own about her cervical cancer’s origins, which blended personal experiences, conjecture, and dominant discourses of cervical cancer:

My theory...because you think of this stuff, is the abusive relationship I was in in high school...I was monogamous and I thought my partner was monogamous but he wasn’t. And he was actually very promiscuous. And when I was with him, I did get diagnosed with an STD...Part of me wonders if those cancer cells were there at that time and they just laid dormant until my pregnancy. And in pregnancy your hormones go like crazy and that activated the cancer cells that were already there...There’s no reason why I should, but I hold my ex-partner responsible for my cancer.

We can see here that her story seems to remoralize her illness, to place it within moral actions, but this is a subjunctive activity involving an array of different causal ontologies, particular multiple biomedical origins. To begin with, she resisted genetic discourses around young adult cancer in favour of a *germ theory* of disease, a discourse more specific to cervical cancer⁵. She thought she may have developed cancer from a sexually transmitted disease her ex-partner transmitted to her and later in the interview she specifically named the human papillomavirus as a possible candidate. Jeanine also evoked a *hormonal theory* of illness as well, which also has

⁵ These two discourses are both rooted in biomedical rhetoric of cancer, but the latter is notably more moralized. Neither Jeanine nor any of the other young adults I talked to were expressly or totally against biomedical ontologies; rather, they were often critical of what they saw as depersonalized, oversimplified and reductionist explanations that tore experiences of illness out of the life histories within which they occurred. In this case, Jeanine preferred discourses that could be weaved into her sexual, relational, and reproductive history.

some bearing in biomedical discourses. She suggested the cancerous cells created by her STD may have been “activated” by the hormones produced when pregnant, what in oncology are called hormone receptor-positive cancers (see e.g., Piccart-Gebhart, 2010).

Of course, there are things she said that would not be well received by her physicians and oncologists. Her moral explorations extended beyond loosely biomedical theories to include interpersonal and psychological ontologies, particularly around her former relationship. These origins were validated when she talked with other cervical cancer patients: “There’s a lot of diagnoses after divorce or pregnancy...obviously a hormonal level and an emotional level.” Coinciding with HPV transmission and hormonal “activation” is a proposed somatic manifestation of emotional distress produced in relational disputes⁶. Jeanine talked about suppressing her distress during and after her “abusive” relationship, which she believed contributed in an unspecified way to her illness.

Jeanine’s cancer was overladen with subjunctive explanations, as any of those causes could have been used to fully explain where her cancer came from. Some of her ‘platforms’ were explicitly moralized accounts (e.g., spousal abuse, contracting an STD, suppression of emotion) while others were less so (e.g., hormone production during pregnancy), but they were entangled in each other, complicating any conclusions we may make about her attempts at remoralization. Her moral explorations provided some sense of meaning, not by singling out a particular orderly story but by multiplying the possible factors that may have in part or in whole caused her cancer.

Furthermore, she described her origin “theory” as not “rational” and gave similar disclaimers throughout the interview, and later admitted, “it makes me feel maybe like I have more control over it and more understanding.” While she said she was compelled toward these

⁶ Outside of emotional suffering I make no inferences about the kinds of “abuse” Jeanine suffered in her relationship, for she never mentioned any other.

causal ontologies, she also seemed to deconstruct them herself, showing them to be suspect in their ‘irrational’ and conciliatory nature. She was also aware of contradictory oncological discourses that provided relief from feeling personally responsible. In a complicated and inconsistent way, then, Jeanine resisted her own efforts to remoralize her cancer.

2. George’s Explorations: Solidarity and Exploitation

George used some similar and some different platforms for the construction of his narrative. He spoke about life before cancer as a time when, “I just want[ed] to work and have stuff and do things that normal people do.” He saw his post-secondary education as “a means to an end” and regretted that he did not “just enjoy the journey.” Like Jeanine, he pitted his unreflective past against his cancer experiences and an emerging concern for where he was going in life. Before cancer, he said he had vague ideas about “settling down and having a family,” but he did not quite take them seriously. After being diagnosed and then witnessing two friends with cancer die, he admitted rethinking his life, saying to himself “I really needed to not take my life for granted,” and thereby ‘initiating’ his explorations for finding his “place” in the world.

One of the primary moral struggles he encountered was around being with his family. He felt that he “never appreciated enough” the support from his wife and the fact that they had lived with cancer together longer than they had been married. He said after his relapse he took on a mission of creating “solidarity” within his family, bringing them closer together. Sadly, he and his wife were not able to reconcile the conflicts that had materialized from over a decade of dealing with cancer; they eventually separated. However, they agreed to preserve some “sense of family” for their children by cooperating with childcare. This sustained involvement with and effort for his family reframed his moral explorations within a more local sphere.

Juxtaposed against this more local moral order, George also considered cancer within the context of contemporary, globalized society. He says, “I’m convinced that a significant amount of the cancers in the world are environmental or social-environmental.” Included under the umbrella of “social-environmental” origins were poverty, pollution, and natural environment degradation, perceived to result from exploitation of people and resources. Threaded into his story was a critique of industrialization and consumerism, two modern forces that George saw as moral violations to our collective obligations: “We’re so reckless and materialistic...and we never pause to think about the linkages with everything.” In other words, according to George, through abusive treatment we have estranged the people and the land we depend on, are responsible for, and are affected by. George felt that modern medicine is complicit in treating each case of cancer individually and ignoring these social and environmental causes. He challenged the medical system to “instead of treating these problems in isolation, well, it’s just like putting a band aid on something. If you’re not dealing with the rest of the system the problem’s just going to keep cropping up.”

Within these moments of moral exploration, George seemed to be engaging socio-political and environmental-stressful causal ontologies, with an added criticism of biomedical ontologies that fail to grasp the “linkages with everything.” There are some elements of interpersonal (i.e., familial) ontologies in there as well, but less as an etiological model for explaining the causes of his suffering and more as a reconciliatory model for relieving his suffering (more on this in the following section on moral living). He seemed fairly comfortable within these ontologies, in comparison to Jeanine who doubted even her own moral claims. It may thus be said that remoralization *was* a key project in George’s moments of moral exploration—again, through subjunctive assertions about the various worlds at play.

Conclusion: Medical Cartesianism and Overdetermined Causes

Both Jeanine's and George's narratives expressed a multitude of influences in the development of cancer. Jeanine interpreted spousal abuse, emotional distress, hormonal changes, and sexually transmitted diseases as all having parts to play in her cervical cancer. George, on the other hand, blended sociopolitical and environmental explanations with moralizing metaphors of pollution, corruption, greed, and carelessness, a symbolic fall out of grace with nature, each other, and ourselves. These platforms for interpreting their illnesses negotiated and resisted an array of causal ontologies, in turn producing complex moral positions.

Both narratives expressed criticisms of biomedical discourses, though in different ways. Jeanine was reluctant to reduce her cancer's origins to genetics despite it being a readily available explanation that would absolve her of blame. George saw fewer merits in a biomedical model, as he perceived gross ignorance within medicine of underlying social and environmental causes. In either case, the object of critique was the medical Cartesianism strong in form today, maintaining that bodily processes are separate from, perhaps even unaffected by, other processes going on in the mind, in social conflict and abuse, and in our surrounding physical worlds.

The amoral implications of medical Cartesianism did not always serve these two participants well, as it threatened to further their sense of "unhomelike" alienation from their bodies, selves, relations, and worlds. Not only do these biomedical discourses abstract illness from the personal and social lives within which they occur, but they also suggest there is nothing people can do outside of patiently receiving their surgeries, chemotherapies, or radiations. Shweder (1997) explained that this may not help many people who "feel as though their illness was a meaningful intervention in an intended course of action" initiated either by their own or another's doing (p. 161). In many of their moral explorations, Jeanine and George among others

within this study criticized biomedical discourses they saw as empty of moral understandings and, consequently, stripped suffering of any purpose.

On the other hand, there were moments in the young adults' narratives in which medical Cartesianism was validated, as can be seen in Jeanine's tense relation (in the previous section on existential questioning) with the claim that there is "nothing at our age we could've done to get cancer." She conceded that this perception may actually "empower" some people. As noted in chapter 5, taking personal culpability out of cancer can be a favourable proposition to some narrative identities (e.g., patients, victims, tragic figures, etc.) and a contentious one to more self-assertive identities (e.g., warriors, healers, advocates, etc.). Though on a philosophical level I criticize medical Cartesianism for abstracting disease out of personal and social life histories, on the level of individual narratives the discourse may sometimes relieve people of blame for their own suffering. Perhaps it is more accurate to refer to the discourse in these moments as patient Cartesianism, seeing as it may be put forth by patients' own initiative without (or against) the suggestion or pressure of any medical staff.

Finally, biomedical discourses were not always in opposition to other causal ontologies. There were times in the narratives when medical and other explanations were expressed together, in "medico-moral" terms (Harris, 1989), as in Jeanine's multifaceted story. Biomedicine does not always promote a discourse of 'you've done nothing wrong.' Disease may be constructed as arbitrary, but recovery or management of it may be perceived as patients' responsibility⁷. Medical discourses can also reify estimated 'risk factors' as indubitable causes, especially around lifestyles. Remember Lorena, who said healthcare providers often wrongfully accused

⁷ Recall, for example, the oncological discourses around young adult cancer I criticized in chapter 2, which concluded that their poorer outcomes are disproportionately due to patient procrastination and non-compliance. We can see here how the ideology of young adulthood within oncology may enter into a medical Cartesianist framework, emphasizing personal responsibility despite maintaining 'amoral' or 'arbitrary' origins of disease.

her of being a smoker, which answered *their* questions about her lung cancer but did not satisfy her. Medical discourses may not always keep causality removed from patients' personal and social lives, and when they don't, they tend to emphasize personal responsibility.

Thus, the young adults toed the line between moral order and disorder, with their overdetermined origin stories and persistent existential questions. "The central moral quest," noted Hyden (1995), is not necessarily to assign responsibility to one's illness, but to "find out *to what extent* the illness event is a result of the kind of life the person has led" (p. 82; my emphasis). Moral explorations, as I have described them, do not definitively make moral sense of cancer and may be regularly characterized by multiplicity, uncertainty and impermanence (see Figure J4). We shall see below that these ambiguous moral meanings have important implications for the young adults' ideal moral lives.

C) Moments of Moral Living

Overview: Ethical Directives toward Moral Lives

With overdetermined etiologies often comes an array of reconciliatory models for undoing or resolving moral suffering. These may be seen as ethical directives for living "moral lives" (Kleinman, 2006), or as answers to existential questions about *where am I going?* Though there may be innumerable cultural discourses around what constitutes a 'moral life,' I want to confine my analyses to what Shweder (1997) called the "Big Three" that are most common throughout the globe: ethics of divinity, ethics of community, and ethics of autonomy (p. 138).

An *ethics of divinity* constructs morality in terms of "regulative concepts such as sacred order, natural order, tradition, sanctity, sin, and pollution" (p. 138). Seldom did the young adults make strong references to moral lives involving divinity or the sacred. They spoke of needing "faith," "prayer" and "God" to get through their illnesses and back onto personally meaningful

life paths. For instance, Martha spoke of her Catholicism as a guiding light to dealing with her non-Hodgkin's lymphoma: "my faith gave me a context to understand my mortality." The phrase "everything happens for a reason" was often appended to statements about what was 'learned' from cancer that could be put into everyday being-in-the-world, like how to be "grateful," "thankful," or have "appreciation" for each day. Some talked—in a more subtle way—about being "blessed," suggesting they were 'given' certain tools, people, and circumstances that would protect them and ease their pursuit of moral lives.

Within an *ethics of community*, emphasis is often placed on the "moral integrity of the various stations or roles" that are of importance to one's local social world (Shweder, p. 138). Duties to others and membership obligations take front and centre. About half of participants constructed their moral lives as communal responsibilities, emphasizing their desires to "contribute" in some way to society, being more concerned about the well-being of "others" (e.g., other patients, friends, or families), and placing "connection" or "family" first above all other obligations. They talked about wanting to be a "good example"—embodying heroic figures that inspire others who are in crisis—and of feeling they have more "empathy," "compassion," "patience," and "appreciation" for the people around them as a result of living through cancer. In these moments of communal ethics, moral lives centred on alleviating suffering in local (and global) social worlds.

In an *ethics of autonomy*, according to Shweder, directives are usually aimed at maintaining individual freedom and asserting personal responsibility, protection of one's rights and from harm, and care for the self (however defined). Within these discourses, a major instruction is "to promote the exercise of individual will in the pursuit of personal preferences" and "the point of moral regulation is to increase choice and personal liberty" (Shweder, p. 138).

The young adults' narratives had far more moments of self-oriented ethics than any other ethical discourse. Most of the time moral lives were constructed around perspectival changes, such as seeing the world with a "new set of glasses," finding "light" or gaining "perspective" on suffering, acquiring a different, usually more "positive," "outlook" on life, and so on. Typically, having cancer was talked about as an edifying experience, "teaching" people to "make the best of it," "live for the day" or "live life to the fullest," see "life as a gift" or "treasure," "focus on what you have," see recovery from cancer as a "second chance," "reevaluate priorities" in search of "what matters," and many other succinct prescriptions.

Many of the directives toward autonomy encouraged preparatory action for future life disruptions. These moments included suggestions to "deal with each day" as it comes, to "take control" of one's care and advocacy, "grieve and move on" from past suffering, "take care" of oneself, and "prepare" for unexpected challenges (e.g., save up for financial security). The oldest of the interviewees, Johnny, made a similarly practical suggestion for living with cancer: "Be aware of what's next and what's plan B, what's plan C, you know? Cause you know what plan D is...The funeral." In talking about how to live with breast cancer, Beth drew up the poem "Advice to my son" by Peter Meinke (2001), which, according to her, insisted on preparing for a future that may or may not happen. She said:

Sure live in the short, like live every day like it's your last but for goodness sakes plant vegetables, because chances are you're gonna survive, you know. And don't just drink wine, you know, have bread too because you can't just live on beauty, like you have to sustain yourself, you have to, you have to make sure that you think long term while you're enjoying every day.

Beth was arguing for what could be called a more active mode of care, inviting people with cancer to take charge of their own recoveries. These ethics of autonomy seemed, for the most part, to encourage individual responsibility for illness and its moral struggles, in a way repeating

dominant discourses about independence and personal culpability, as discussed in chapters 2 and 5 in relation to young adult oncology and narrative identity (see e.g., McAdams, 2013; McGoldrick et al., 2011). In sum, the imperative of self-authoring one's life, including one's responses to disruption, seems to operate within an ethics of autonomy.

Each of the three aforementioned ethics tend to assume the existence of certain cultural entities (i.e., gods, social collectives, or selves, respectively), for whom one must care in order to achieve moral living. Within the young adults' narratives, these assumptions were sometimes doubted or criticized. Instead of living for God, another person, or oneself, existential questions about how to live and who to live for were not quite answered. A fair minority of young adults said they "try not to think about" their cancer or what it meant for the rest of their lives; they felt "very lucky" to still be alive, but admitted that they "can't predict or control much" of the future, seeing that there are "no guarantees" that any moral action will assure a better or longer life. They believed that "life sucks" and there is "no reason" to their suffering, that their cancers "won't ever go away" or "can come back anytime" and "quickly."

In these *moments of ethical uncertainty*, it became quite a task to affirm some moral standards for living. When we look at specific narratives we often see subjunctive moments exploring multiple moral lives—lives with oneself, lives with others, and lives with the great beyond (i.e., fate, God, and the unknown); in Jeanine's and George's cases, ethics of autonomy and ethics of community were in frequent dialogue. Between these different paths is an implicit recognition that any moral life may be pointless, mistaken, or foreclosed, for past paths have not always turned out well and it can never be known what lies ahead.

1. Jeanine's Moral Lives: Caring for Oneself before Others

Jeanine concluded that cancer can “hit anybody, everybody,” that there are “so many different faces to cancer” the disease seems to hold little rhyme or reason, including her personal causal ontologies. In the face of this unpredictability, she held herself primarily accountable for the effectiveness of her treatment. She spoke of wanting to take charge of her own care, making more meticulous decisions. She said, “the best I can do for myself is take action and responsibility for the decisions I am going to make for my future treatment.” This dictum came out of the history of treatment choices she later regretted. She said her moral involvement in cancer was to become an authority on her care and a source of knowledge about her body. There is a current of reconciliation under the following statement: “while I maybe didn’t make the right decisions, I am going to take those decisions and make them right.”

Note that for Jeanine the past was couched in terms of moral decline—she says she did not make the “right decisions” before—while the future was positioned as moral resolution—she will “make them right.” Many young adults’ moral quests expressed these hindsight, implying that past illness and suffering could have been prevented, and future suffering may be avoided with certain life adjustments. In the following statement, Jeanine indicated what adjustments would lead her to a more moral life:

I wouldn’t say that it has made me want to go sky diving, or live life to the fullest – take that ‘carpe diem’ approach everyone describes. Cancer has more just made me appreciate the small moments I have in my life like getting to spend time with my daughter, and family and friends, and brought me to a place where I can slow down the fast paced, people pleaser life I previously lived, and live a little more for myself.

Beyond her treatment decisions, Jeanine saw for herself a more general program of self-care in order to heal her emotional wounds and protect against future suffering. She rejected what she saw as a cliché “everyone” uses to refer to the life not taken for granted. Some moral quests, she

reminds us, are traveled without leaving home, as people come to “appreciate” what is in their lives already. Furthermore, she says, “[I’m] wanting to live my life differently...I don’t want to waste my time not being happy because I don’t feel I have a lot of time to waste not being happy.” “Being happy” means “follow[ing] my own expectations,” “enjoy[ing] the time I have with friends” and maintaining “healthy and positive” relationships with others (i.e., not getting into situations of abuse).

We can see a strong reference to both ethics of autonomy and community in Jeanine’s moments of moral living. She saw her ideal “place” in the world as an advocate and supporter of others, but could not achieve that moral life quite yet: “My role in life was to take this experience of having cancer, was to turn it into something to help other people...but I need to care for myself first.” The emotional distress Jeanine said she experienced in her former relationship as well as during her cancer treatment seemed to be on-going, a daunting relic of her “survival” phase that she had only begun to address. She wanted to get involved in care for other cancer patients, but had to put it on the “back burner” because her own needs had not yet been provided for. In a sense, for Jeanine an ethics of autonomy may enable an ethics of community—one moral life may open the door to another.

2. George’s Moral Lives: Individual and Collective Change

George had his own moments of ethical uncertainty, recognizing that “I’m going to be limited” in abilities in the future: “I’m not going to pretend I’m like perfectly healthy...that’s ‘mental gymnastics.’” His cancer returned after an extended period of remission, which George’s doctors believed “doesn’t ever happen in that length of time apparently.” His rare circumstances notwithstanding, he felt that cancer is not a thing of the past and will be with him (in memory, in side effects, perhaps in relapse) for the rest of his life.

Though doubtful that he would be rid of cancer no matter what he did, he echoed some of Jeanine's feelings around "fast paced" life and its trappings. He recalled feeling the "pressure, responsibility and time commitment" of having a "high-paying job." After living with cancer, which likely slowed down his career life and chilled his rise in income, he described moving away from these goals. He had become, in his words, more drawn to "real problems" in the world, having to do with the social inequities and environmental injustices to which he traced his cancer.

George spoke of his cancer as a "sign" not only that he personally needed to change his lifestyle, but also that the world around him needed changing. In terms of the former, one of the most salient issues for him was his perspective. By this he appeared to mean that he did not want to see cancer and its treatment as a "war" or battle. He said this frame of mind might get people caught up in notions of winning, of overcoming cancer, and leaving it behind. By contrast, chronic diseases like cancer can be unfazed by aggressive attempts to destroy them, can come back several times, or can leave lifelong scars and crippled bodies. Underlying these statements George seemed to be asking, what chance do people have of conquering such adversaries?

George argued that cancer should instead be seen as a "journey," not a "fight," one in which patients meet "fellow travelers" and other kind souls along the way (see chapter 4 for more elaborate distinctions between these two tropes). For himself, this shift in metaphor allowed him to "embrace" his cancer: "If you were going to get it anyway, and you embrace it and the lessons you learn from it, I mean, it teaches you a lot about what's important in life." He described acquiring a sense of "calm" from taking on this attitude of 'listening' to cancer. He had also become, as he says, "pretty fond of who I am now."

For George, ‘embracing’ his cancer meant an ethical practice of evaluating what may be gleaned from harmful suffering. Thinking of Lance Armstrong’s claims about being grateful for having cancer, he says, “If you had to choose to not have cancer, you would. Don’t be an idiot.” Following along his pedagogical metaphor, I might say: people would be better off if they did not have to go to a class on life disruption, but for those who are already in session they might as well take notes.

Given his concern for local and global worlds, George believed also in an ethics of community: addressing “social determinants of health,” creating “community cooperatives,” cleaning up “toxic environments,” reducing “economic disparities,” and so on. Moral living for George meant a modified social structure within which people acted more cooperatively together, and were more attentive to the “linkages with everything.” Though he understood moral life on a conceptual level, he struggled to “operationalize” his roles and objectives within such collective actions. He admitted feeling too “tired” and lacking “more discipline” to actually engage in advocacy work: “I know these things, I just haven’t done them yet.” He indicated that he wanted to “make a difference” and “to be useful” to others, but he needed “clarifying” of what he could do.

George’s difficulties in identifying a concrete plan for a future moral life ring true of many other young adults’ ethical directives. Their existential questions about life purpose continued for years after treatment and into their interviews. Their moral quests did not necessarily route back to where it began in a complete circle, but instead continued indefinitely into the open horizon. That future work needed to be done, from their perspectives, precluded a neat resolution to their moral struggles.

Conclusion: The Limits of Remoralization

It seems that, like etiological models of causal ontologies, reconciliatory models in the young adults' narratives may also be overdetermined, coexisting within their moral quests (see Figure J5). We may suggest from these observations that remoralization, that is, re-positioning suffering within moral terms, is an on-going and unstable process of interpreting pasts, presents, and futures; remoralization sometimes may be desired as people seek order and direction, while at other times may be resisted or disrupted when people sense the potential uncertainty and futility of moral living. Exploring multiple ethical directives may open up a variety of moral lives for young adults, enabling pursuit and critique of different hopes and futures.

These propositions rub against more familiar, and more prescriptive, understandings of moral quests that seem to fuel the imperatives of narrative coherence and self-authorship. According to Arthur Frank (1995), for example, a quest narrative “recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice” (p. 134). In this conception of quests, not only is remoralization asserted as a necessity to witnessing suffering, but also an ethics of autonomy is thrust onto narrators through Frank’s assertions of personal “responsibility” and “moral agency.”

Other critical assessments of moralized illness narratives seem to prefer remoralization as well. Shweder (1997), for example, defended moralizing discourses that attribute personal responsibility to illness because they give people direction in how to address and heal their suffering (p. 160-165). He suggested that moral discourses of illness are preferable to discourses in which illness is portrayed as “chance” or an “accident” (p. 160). In fact, he had some harsh words for attempts to minimize responsibility and blame within biomedical discourses:

Suffering is decontextualized and separated from the narrative structure of human life. It is viewed as a kind of ‘noise,’ an accidental interference with the life drama of the sufferer.

It is as though suffering had no intelligible relation to any plot, except as a chaotic interruption. This image of suffering is most congruent with a theodicy that asserts that suffering is and must remain a mystery because it has no existential meaning or purpose (p. 159).

Shweder suggested that these discourses, which seem to express medical Cartesianism, can steal away hope, value, and focus from people's stories of illness, and are inadequate to the remoralizing task of portaying illness "as a meaningful intervention in an intended course of action" (p. 161). Arthur Kleinman (1988) agreed that biomedicine may take away moral considerations and "cannot provide" for the "need to make moral sense of" patients' existential concerns (p. 20, 29). We can see here a dominant academic discourse in favour of reconstructing moral orders in the midst of crisis.

If, as I have shown, moral quests only sometimes lead to affirmations of certain moral orders, and the whole process has only a "provisional ending" (Hyden, 1995, p. 72), then how can we justifiably make it an imperative? I do not believe we can. Remoralization is not *inherently* beneficial, but can sometimes be dangerous, encouraging stigmatization, deceptive myths, victim-blaming, and related forms of distress among patients. Sometimes a moral stance is not possible or, more often, not desired; recall that some of the young adults themselves cultivated Cartesian views of disease. In their challenges to and doubts about causal ontologies, many of my participants sometimes went *against* remoralization. In these moments of meaning their moral quests were put on hiatus or steeped in mystery, and I would disagree with Shweder that mystery plots are all bad. Destabilizing or deviating from remoralized accounts of illness can be an empowering form of resistance, when moral orders seem oppressive and suffocating in their assignments of blame.

Sometimes the above narrative scholars recognize the limits to remoralization, and I want to draw attention to these admissions. Frank's (1995) chaotic narratives, for instance, may

exemplify stories that are somewhat lacking in moral orders, and on his own accord he pleaded for an “enhanced tolerance for chaos as a part of a life story” (p. 111). Shweder (1997) also admitted, rightfully so, that, “It is probably advisable to avoid a dogmatic preference for any one discourse of health, suffering, and well-being” (p. 165), even while he flagged his own preferences. Kleinman (1988) also noted that one way to transform or transcend one’s illness experience is to realize the “chaotic” and “capricious” aspects of life (p. 55). In a later book, he referred to any discourse asserting orderliness to suffering as a “big lie,” a reckless “denial of existential vulnerability and limits,” and ultimately a damaging ideology (Kleinman, 2006, p. 7).

Perhaps making moral sense of illness is not the sole task of moral explorations. Moments of possibly absurd or uncertain realities are important and frequent productions within people’s narratives. It may be that, as best put by Kleinman (2006), “when the denial [of chaos] becomes so complete that we live under what amounts to a tyranny of not seeing and not speaking the existential truth, it becomes dangerous itself” (p. 8). There is a truth to mysteries and chaotic narratives as well, to moments of meaning lacking moral certainties, as they speak of the dangers of moralizing what very well could be arbitrary suffering.

Chapter Conclusion: Critical Witnessing of Moral Quests

Moral quests sometimes remoralize people’s lives, placing them into larger contexts of causal ontologies. So far we have looked at the significance and limits of remoralization; underlying my conclusions is an important ethical issue, requiring a shift of attentions from narrators to their audiences⁸. Philosopher Paul Ricoeur (1988) once noted that reading or listening to a narrative “turns up as an interruption in the course of action and as a new impetus to action” (p. 179); in other words, stories of suffering may instigate reflection among audiences

⁸ Although social scientists were the main intended audiences of the narratives, the participants said they hoped their stories would reach other audiences as well, including other cancer patients, their significant others, care providers, and the general public.

on their own moral experiences and lives, affecting their meanings and actions. Given the wide range of causal ontologies and ethical directives constructed in the young adults' narratives, audiences inevitably come into contact with contradictory moments of meaning. How, then, do they proceed? What do they do with conflicting stories of suffering that strive to instill them with an "impetus to action?"

There is a wide spectrum of ways to 'receive' illness narratives among academic audiences. We may plot these different responses along a continuum between what Paul Ricoeur (1976) called "appropriation" and "distanciation" (p. 43). Some camps lean more toward the former, prescribing audiences to listen empathically and to *appropriate* the 'lessons' of illness narratives into our understanding. Arthur Frank (1995) seemed to advocate this approach, claiming that audiences have a "moral duty" to bear "witness" to and become recipients of others' causal ontologies; in other words, seeing patients' moral lives as possible ideals for themselves (p. 128). Unlike his imperative for narrators, his expectations of audiences are heavily anchored in an ethics of community, where their responsibilities are to 'honour' the stories—and their possible causal ontologies—of others.

Frank and others encourage audiences to be "witnesses" to stories of suffering, for they believe illness narratives speak the narrator's personal truths and need to be recognized and legitimated (e.g., Charon, 2006, p. 53; Frank, 1995, p. xii-xiii; Kleinman, 1988, p. 10). This ethics is founded upon a reader response theory of narrative as testimony: "The moral genius of storytelling is that each, teller and listener, enters the space of the story for the other... Thus all stories have an element of *testimony*" (Frank, 1995, p. 18; original text). There is an alleged therapeutic effect to taking on the role of witness: "people can only be helped out when those who care are first willing to become witnesses to the story" (Frank, p. 110).

For other camps of reading, maintaining some critical *distance* from illness narratives serves a very different imperative, namely, to challenge base generalizations and unjust moral claims, for they may perpetuate suffering in spite of offering instructions against suffering (e.g., Good, 1994, p. 56-62; Jureric, 2012, p. 3-16). Literary theorist Anne Jureric (2012) saw an undergirding assumption to this approach: “we need critics in order to understand how ideological constraints transform sympathetic readings of others’ suffering into acts of complicity with the systems that produce that suffering” (p. 14). Distance, it is believed, prevents audiences from being sucked into an ideological world explaining suffering in moralized terms—just as Voltaire’s poem at the beginning of the chapter pleaded ‘witnesses’ of the Lisbon earthquake to step away from prevailing theodicies.

According to these ethics of critique, honouring moralized stories may actually turn a blind eye to oppressive dogmas. For instance, sympathizing with distress caused by an arm amputation may implicitly support dominant ideologies that *construct* amputation as a form of deficiency: cultural expectations of productivity and efficiency in work ethics; ableist ideas about bodily integrity equaling personhood; dominant aesthetical judgments about what constitutes beauty or other ideal body types; and so on. By criticizing these cultural biases, and how they are evoked in the narratives of people who suffer from them, we are participating in a larger, socially transformative project of breaking down oppressive ideologies. By extension, moments of meaning that do not seem to remoralize illness or espouse particular causal ontologies may be praised as resistance to burdensome and pejorative moral discourses.

How do we proceed in the face of these competing imperatives? Perhaps a conversation is possible between them through what could be called *critical witnessing*, an ethical practice of recognizing a multitude of moral quests that take off in different directions and arrive at an array

of ‘provisional endings.’ Recall in chapter 3 that my response to the ‘crisis in illness representation’ was to use a dialogical methodology—critical phenomenology—that maintains a conversation between multiple distancing and appropriating perspectives. ‘Critical witnessing’ could be seen as an extension of that practice into ethical disputes over moralization, admitting that while remoralization may sometimes provide hope and direction, its absence may also sometimes alleviate moral pressures and social judgments.

While our participants may promote an objective, *moral realism* in their stories, we may need to maintain a *moral relativism* in our reception of their stories (Shweder, 1997), meaning each moral claim is situated within local contexts of personal desires and intersubjective meanings, with a more or less internal logic to it and some insight into human experience, but not necessarily possessing any external logic beyond it. In Shweder’s (1997) words, a certain “casuistic flexibility” is required of professional listeners in order to attain “a general awareness of possibilities for expanding our discourses of health and responsibility” (p. 165).

I demonstrated the practice of critical witnessing throughout this chapter. On the one hand, I placed the young adults’ moral quests within their personal life histories and in relation to dominant causal ontologies. In a sense, I attempted to take their journeys with them, paying just as much attention to moments of questioning, exploration, and uncertainty as to seemingly certain moral meanings about life during illness. These interpretive practices enabled some appreciation of where the young adults’ (resistance to) remoralization came from. On the other hand, my encounters with local meanings and subjunctivity opened a certain distance from them, seeing in them expressions of circumstances that are not universal and cannot be extended to other young adults with cancer. This distance exposed remoralization as an overgeneralized imperative sometimes operating on people who are ill and those who listen to them, leading me

to challenge some basic assumptions about moral quests on the basis that moral order is not always at stake in people's stories. In this way, we can see that appropriation and distancing may build upon one another, that, in Ricoeur's (1986) words, "we can no longer oppose hermeneutics" as the avenue toward witnessing and "the critique of ideology" (p. 88)..

By focusing on local contexts and multiplicity does not mean we forsake any attempts at generalization; what it means is being extra-sensitive to the specificity of stories, finding the limits of the worlds they construct, before working our way to their broader appeal and relevance to others. Moral discourses need not be met with an 'either/or' attitude, either witness or dismiss them; through an ethical practice of dialogue room may be made for a wide spectrum of stories to be heard, shared and validated but not generalized beyond the circumstances of their production.

The Polysemantics of Illness Narratives: Living with Complexities and Chronicities

My research began by critically evaluating much of the previous research literature on young adult cancer; not simply a literature review, this evaluation was defined predominantly by a “hermeneutics of suspicion” (Ricoeur, 1970), intended to create a critical distance between some of the most basic assumptions held within certain dominant discourses and, correlatively, open doorways to alternative ways of thinking and listening to stories of cancer. Inspired by Kairol Rosenthal’s book on young adult cancer, *Everything changes* (2009), my primary objective was to reveal multiplicity of meanings and ways of being that I did not find represented in the discourses.

My analytic chapters brought forth the “polysemanticism” (Ricoeur, 1984) of illness narratives, the power and flexibility of individual stories to signify a plurality of existential and biographical challenges. I begin this chapter by summarizing these diverse symbols of lived experiences. The next step is to elevate my findings into discussion of some derived implications of this study. Finally, I would be naïve if I did not direct my hermeneutics of suspicion inward; I end my dissertation by noting some of the limitations of the research and proposing what may be done in the future to further our understanding of cancer in young adult lives.

Summary of Findings

I tried to embody in this dissertation the complexities that I saw in the young adults’ narratives. I covered a lot of ground in not a short span of pages, striving to achieve a critical phenomenology of what Rita Charon (2006) perceived as clinically relevant features of illness narratives: time, frames/forms, characters, ethics, and teller-listener relationships (p. 40). I

modified these categories into narrative genres (ch.4), identities (ch.5), and moralities (ch.6). Let me briefly resurrect the liveliness of meaning and being within the young adult cancer narratives.

In chapter 4, I showed that the young adults shaped or formed their narratives in dialogue with, on the one hand, prototypical plots they had encountered in their lives and, on the other hand, their own personal purposes for telling their stories. Most frequently in their narratives they expressed *moments of sojourning*, describing physical journeys to the hospital, mental tours of personal and social expectations, banishments from life as it was previously known, and travels into the land of the dead. Second most common were *moments of healing*, whether from medical interventions, serendipitous circumstances, or self-transformations. *Moments of fighting* emerged less often than I had expected, but they were still quite noticeable, speaking to battles with cancer itself, political struggles with people who seemed to get in the way of recoveries, and athletic obstacles toward self-transcendence.

Two other, less known narrative forms also emerged from my reading of the young adults' stories. *Moments of inspecting* included stories of mysterious symptoms, criminal plots to rob or kill protagonists, and breached borders between selves and enemies. Finally, *moments of disordering* produced chaotic narratives that exposed lapses of meaning and coherence in the young adults' stories. The array of narrative forms, as well as their many 'enabling' and 'disabling' effects (e.g., emotional, hermeneutical, relational, and practical), suggests a plethora of ways and purposes to express illness experiences, more than is recognized in the relative emphasis on narrative coherence in dominant discourses of young adult cancer. We may conclude from this analysis that while attending to the inspirations of prototypical plots helps to contextualize illness narratives, our understanding depends on seeing how they are innovatively negotiated within individual stories for personal purposes.

In chapter 5, I discussed the multiplicity of narrative identities performed in the young adults' narratives. Fundamental to this diversity is the notion of *liminality*, a narrative process of shedding old selves, living in-between different selves, and sometimes acquiring new selves. The identities at stake related to cultural 'myths' around illness and young adult development. Within the various moments of meaning from chapter 4 were expressed moments of (non)being: in less liminal *moments of being* the young adults emplotted themselves as survivors, patients, warriors, detectives, and advocates, and in more liminal *moments of non-being* they emplotted themselves as victims, exiles, self- or co-healers, phoenixes, and tricksters. Sometimes the latter were emphasized or even favoured, suggesting that identity 'consummation'—often expected to follow liminal experiences like cancer treatment—is not always possible or, more importantly, not even desired while living with a chronic illness. Looking to myth, it seems, may illuminate how people interpret themselves during periods of crisis.

I also supplied additional contexts to the young adults' narratives, highlighting different forms of intersubjectivity that co-constructed their moments of meaning and (non)being. I studied the varying negotiations with others, both more "peaceable" and more "hegemonic" interactions (Crotty, 2003) between involved horizons of expectations. Clinical relationships contained moments of mutual and of disputed therapeutic emplotments, while the young adults' local worlds were sometimes inclusive and other times alienating. Cancer patient communities often filled the gaps created by this alienation, taking in individuals who felt lost and isolated. Nevertheless, created under the pretence that young adult cancer is 'distinct,' these communities risked becoming ideological and divisive by glossing over diversity within them and minimizing similarities outside of them. These different intersubjectivities were threaded into the young adults' narratives, essential to their composition and difficult to tease out from the young adults'

own voices. I made the case that before we make conclusions about the young adults' perceptions of their cancers or themselves, we need to consider how the people within their stories may be writing in their perceptions as well.

With regard to developmental identities, the young adults engaged with some cultural tasks of adulthood—such as health, independence, marriage, children, property ownership and a stable career—tasks that are built upon assumptions that generativity is inherently linked to narrative coherence and self-authorship. Some of these milestones were foreclosed to the young adults and some were not wanted, even before cancer. The narratives seemed to wrestle with developmental identities in order to determine which were both possible and practical, often requiring revaluation and renegotiation of dominant meanings of generativity. This shift suggests we must rethink our concepts of development, identifying less with markers of 'achievement' and more with changing participation in social life, such as contributing critical voices to dominant discourses and the practices they encourage. I proposed that, instead of looking for 'grand' identities that presuppose narrative order or self-authorship, it may be more informative to study the diverse and critical identities that occur in temporary moments of illness narratives.

In chapter 6, I took into account issues of morality. Often told as journeys or *moral quests*, these moments of meaning reasoned through dominant causal ontologies of suffering. Often initiating their moral quests were *moments of existential questioning*, during which they expressed feeling lost and confused about who and where they were in life. These moments came at unpredictable times, sometimes in the midst of treatment, sometimes well into post-treatment. The young adults spoke also of departing upon *moments of moral explorations* where they traversed multiple platforms for emplotting their experiences, sometimes arriving at provisional endings about where their cancers came from. They entertained a number of different causal

ontologies, rooting cancer variously in the interpretive frameworks of biomedicine, interpersonal relations, socio-political conflicts, environmental stresses, rational determinism, psychosomatic mechanisms, and absurdity.

During *moments of moral living*, their explorations turned toward possible futures, and engaged with ethical directives for coming out of their suffering. These directives were most often framed in terms of personal autonomy, communal responsibility, and (much less so) divine obligations. Across the different moments of meaning reflecting on the past and the future, the young adults constructed overdetermined positions on the morality of cancer. At times they were resistant to moral explanations, and other times frustrated by explanations not explicitly moral. This diversity makes it difficult to follow through with the ethical imperatives often placed on audiences of illness narratives, for how do we witness contradictory ‘truths’ at the same time? My answer to this question was that *critical witnessing*, a dialogue between distancing from and appropriating moral meanings, may enable audiences to situate young adults’ stories within local personal and social contexts, thereby recognizing (resistance to) local moral orders without extending those orders into the lives of others.

The recurring motif of my analyses was that the ideological construction of young adulthood meets its limits in the realities of young adult cancer, whether we’re looking at the construction of meanings, selves, or moralities. Thus concluded my critical phenomenological analysis of the young adults’ narratives. What may we derive from these findings? What may we say more generally about young adult cancer or, indeed, cancer across the ages? Let us enter into discussion of the broader implications of this study.

Implications in Research and Healthcare

Throughout this dissertation, I tried to juggle recognition of young adults' performances of meaning and (non)being with critical evaluation of their stories' social implications. Above all, I tried to avoid essentialist language that would reduce the stories I heard to immobile genres, identities, and moral positions. Nor did I wish to talk in the mechanical language of psychosocial 'adjustment,' as though all that was at stake for them was adapting to life disruptions.

Adjustment is an outcome of particular interest in some oncological discourses inside and out of young adult cancer (see e.g., Cella and Tross, 1986; Mumma, Mashberg, and Lesko, 1992; Roberts, Piper, Denny, and Cuddeback, 1997; Vickberg et al., 2001). However, as anthropologist Michael Jackson (2005) wrote, "human wellbeing involves far more than simple adjustment to a given environment, natural or cultural; it involves endless experimentation in how the given world can be lived decisively, on one's own terms" (p. xii). Sometimes the most convenient routes, the most readily available plots, the most coherent answers, were not seized upon; sometimes the young adults' main desires were not to hastily return to 'normal,' but to push the boundaries of what they considered a meaningful life—what we may see as efforts to expand social spaces of experiences and horizons of expectation.

Taking language as the illumination of what is at stake during illness and, in turn, the basis of diverse meanings and identities, I interpreted complexities to the young adults' metaphors and narratives that were admittedly overwhelming at first. I cannot even assure readers I've done justice to the rich, wide ranging moments of meaning and (non)being, but I believe I have laboured enough to make the case that there is "endless experimentation" in how the given worlds of young adults who have cancer "can be lived decisively." Below I outline three major implications to the analyses I conducted in my research, namely, that negotiations of

meaning and being in contexts of cancer narratives are incredibly complex, under chronic revision, and in need of critical witnessing. These suggestions are all made with the hope of cultivating sensitivity in how language is used to emplot suffering and pursue healing.

1. The Complexities of Living with Cancer

First of all, as reviewed above, the existential and biographical challenges of young adult cancer are manifold and complicated. Through innovation and desire, each story modifies sedimented meanings and myths into personally relevant emplotments of experience. Very few of the reviewed studies of young adult cancer represent their participants in this way, tending instead to essentialize them, portray them without contextual considerations, leaving readers to infer they are void of history or culture. Ideological readings of cancer and young adulthood helps us to talk about shared experiences and concerns, but they conceal local purposes and contexts under their more simplistic representations. One of my explicit purposes was to shake the pillars of narrative coherence and self-authorship, and I believe I succeeded in showing that integration of experiences and selves were but two among many other stakes, including critiques of order, subversion of expectations, expressing chaos and mystery, displacing blame, and so on. In addition, cancer survivorship was but one of a plethora of coexisting lives to which they were tied. At various times they also narrated themselves as ‘normal’ twentysomethings; as part of a family of spouses, parents, and/or children; as students or workers participating in career development; and so on. Many of the participants said that cancer may be a continual part of their existence but it did not consume the whole of it. This should serve as a reminder to health researchers that for people who are ill there is much more at stake and much more to their life-worlds than simply coping with the travails of disease (Kleinman, 1988).

It is likely, furthermore, that the discourses discussed may reach beyond just young adults with cancer. Some narrative environments overlap across pediatric, young adult, and older adult cancers. I would say, for example, that narratives of battle and recovery, and the identities they tend to construct, span all ages as a more general mode of oncological discourse. Such crossover patterns may pertain to gender as well; though specific cancers can affect gendered forms of meaning and being—such as when cervical or testicular cancers threatened maternal and paternal identities, respectively—the men and women in the study seemed to share many of the narrative forms (e.g., moments of fighting and sojourning), developmental concerns (e.g., with regard to career and health), and moral meanings (e.g., the languages of biomedicine and environmental stress). In this way, across age and gender, participants often contended with and operated under similar symbolic systems of meaning.

2. The Chronicities of Existential and Biographical Challenges

A second major implication to my work is that issues of meaning, being, and morality in the face of chronic illness can be indefinite, possibly life-long endeavours. Recall that liminality typically continued years beyond treatment, whether it was sanctioned or unsanctioned by people's local social worlds. This may not even be limited to experiences of chronic illness, as we consider more widespread young adult experiences as moratoria. The applicability may go even further, as researchers of aging Randall and McKim (2008) wrote, "Right up to our death, we can continue remembering, reinterpreting, and reading our lives, and thus reworking our identity" (p. 62). That reading oneself continues throughout life may be another reason my conclusions extend beyond young adults. Narrative disruptions and reconstructions possibly never come to an end, less so for people dealing with long term effects, remissions, and relapses. Whether a person is 18 or 80, living with cancer can be a *chronically liminal* experience.

This conclusion is perhaps one of the strongest indications that we should question the applicability of concepts of ‘adjustment,’ ‘return,’ or even ‘survivorship’ in contexts of cancer. Recall that the young adults’ moments of meaning and being were often tentative, temporary, and concurrent with alternative or contradictory moments. Words of certainty, including references to being cured, completing developmental tasks, or attaining narrative order and self-authorship, do not seem to adequately represent the chronic experiences of cancer in young adulthood (or cancer in general). At the very least, they do not recognize the enabling effects—the prospects for healing, empowerment, or self-understanding—offered by symbols of the unknowable (e.g., chaotic narratives, tricksterly identities, absurdist ontologies, etc.).

I do not mean researchers of cancer narratives ought to dismiss expressions of recovery, order, and stasis. To do so would disenfranchise most of the people I interviewed and likely the majority of people living with cancer. Rather, I suggest that in our interpretations we should not take such expressions as the last word. We should temper our “willingness to listen” to the suffering of others with a “willingness to suspect” that life is as clear-cut and resolute as our language sometimes makes it appear (Ricoeur, 1970); hence, expanding Frank’s (1995) imperative to hear the truths of stories, I proposed a practice of ‘critical witnessing’ that minimizes the extent to which these truths apply on a more global scale.

3. Critical Witnessing in Contexts of Care

The third and final implication is the potential role critical witnessing may play in the helping professions as well. As demonstrated in chapter 5, those who work with cancer patients are involved in intersubjective negotiations of meaning and being. They read patients’ stories in search of “pathognomic signs” (Kleinman, 1988, p. 16) and, at least among my participants, they often read through a lens of suspicion; for instance, distrusting claims of physical suffering and

offering psychological ontologies in their place (see chapter 4). The chronicities of suffering and felt alienation can be exacerbated by such breakdowns in negotiation. Without sensitive readings of their distress, people have no home for their plethora of existential questions and catalogues of answers. The following implications are directed mainly toward my intended audiences of providers of healthcare and psychosocial support for young adults with cancer.

The therapeutic adjunct of critical phenomenology, critical witnessing maintains a level of suspicion towards narratives of illness, but without disenfranchisement of patients' desires, meanings, and praxes. We could say that critical witnessing entails three clinical practices, the first of which is a reduction of alienation by way of listening. Many of the young adults experienced a heightened sense of unhomelike being because they felt unable to converse with those around them; they were cast out due to the uncomfortable truths they signified simply by being younger persons with chronic illness. A practice rooted in psychotherapy but argued for elsewhere (see e.g., Charon, 2006; Frank, 1995; Kleinman, 1988), non-judgmental listening is tantamount to allowing the expression and eventual healing of distress—that includes the chaotic narratives that are so fringe within oncological discourses.

The second practice is tracking the local therapeutics of meaning and (non)being, that is, their ties to dominant narrative forms, identities, and moral meanings along with the purposes they serve for individual patients. Providing support to people who are ill accomplishes little without having an idea of what is therapeutic to them, that is, the personal contexts of meaning and being (see e.g., Kleinman, 1988). This accomplishes a hermeneutics of understanding, while consideration of broader cultural and critical contexts (i.e., of internalized, resisted, and negotiated hegemonies of meaning and being) maintains a hermeneutics of suspicion as well (Ricoeur, 1970).

The third task is to utilize these empathic and suspicious readings to facilitate dialogue and negotiation toward “therapeutic emplotment” (Mattingly, 1998). Together these readings may situate people’s stories in such a way that their personal ‘truths’ can be honoured but not at the expense of ignoring their dangerous implications if writ large. Thus, again at the local level, a practice of critical witnessing facilitates negotiation by entertaining even the most suspicious meanings while at the same time noting their limitations (e.g., the slippery slope of remoralization toward victim blaming). To be sure, meaning and being are always contested—there are simply too many competing intersubjective spaces to traverse—and no amount of negotiations will come to a resolution. But, perhaps within a ‘safe place’ to have ‘controversial’ conversations people may be able to explore possible ways of living with such tensions.

I see this task as restricted by certain dominant discourses within oncology. In psychosocial oncology, therapeutic emplotment seems to be set within a deficit model of development, where narrated independence and coherence are idealized. In biomedical discourses of oncology, the stakes of young adult cancer have been similarly narrowed down to ‘simply’ survival. Furthermore, reliance on statistical representations to interpret young adult cancer, which pitch it as relatively rare, can get in the way of picking up on signs of cancer within seemingly healthy bodies. Finally, medical Cartesianism can, with exceptions, create a rift between doctors’ and patients’ horizons of expectation as they may situate disease in quite different ways. These selective attentions may inhibit healthcare providers from understanding and working with the diverse array of people who may come under their care, in turn threatening the efficacy of their communication and the prospects of negotiating treatment protocols.

Rita Charon (2006) argued, “a scientifically competent medicine alone cannot help a patient grapple with the loss of health and find meaning in illness and dying” (p. 3). Indeed, from

the perspectives of my participants, scientific knowledge of young adult cancer (including the psychosocial concerns seen to be most common to the age group) is very important but it can also impede clinical judgment and proper care because of its reductive representations. The implications above encourage an additional, complementary practice to reading young adults' stories through the registers of developmentalist and biomedical discourses, namely, by taking a more phenomenological perspective. Charon situated this perspective within what she called a "narrative medicine," based on the following premise:

To know what patients endure at the hands of illness and therefore to be of clinical help requires that doctors enter the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patients' point of view (p. 9).

Entertaining patients' horizons may minimize barriers to hearing their stories, seeing their interpretations of symptoms and disease, and negotiating a therapeutic plot that makes sense to them. It may also, on the other hand, cultivate critical evaluation of therapeutic employment, as "the reader categorizes, analyzes, measures up successes and failures, and deploys critical judgments" throughout the process of care (Charon, p. 112).

Other emerging healthcare discourses have also drawn attention to the life-world of patients. Discourses of "patient- and family-centered care" (see e.g., Dowling, Manthorpe, and Cowley, 2006; Feinberg, 2012) argue that patients' distress and sense of alienation may be exacerbated if care teams do not integrate the "individual's needs, goals, preferences, cultural traditions, family situation, and values" into care planning and implementation (Feinberg, p. 1). The principles of this approach parallel Charon's above: respect and dignity for patients and their loved ones, caring for the "whole" person not just the 'patient,' attending to personal experiences and needs, and facilitating patient empowerment through dialogue and collaboration.

Whether under the banner of narrative medicine, phenomenological medicine, or person- and family-centred care, the quality of oncological care may be enhanced by deliberate attempts to negotiate the different horizons of expectation of those involved in care. I do not mean to say that the above practices are absent in the clinical work of medical and psychosocial oncologists. Indeed, Cheryl Mattingly's (1998) research on therapeutic emplotment effectively demonstrated that it is a common (albeit implicit) activity between patients and their caregivers. My intention is to make these practices more explicit as essential elements to cancer care and, in turn, subject them to critical evaluation, self-reflective use, and improvement.

My research adds to this narrative medicine by bringing into sharper focus some of the implicit (or latent) meanings and identities that are communicated in cancer patients' stories. The moments of meaning and (non)being I have discussed could serve as anchoring points within the process of therapeutic emplotment; in particular, caregivers could use the visuals I have constructed as tentative interpretive frameworks for reading patients' stories, perhaps helping caregivers to sort out what is at stake for them and how they may be counseled.

I have laboured to show that a sense of narrative order and self-authorship are not always the main priorities among people who live with chronic illness, and the terms by which I open up the multitude of stakes in illness narratives may be used to interpret and respond appropriately to those stories. The many moments of meaning I explored could be used to identify the symbolism in patients' stories and the potential frames by which healing and empowerment are emplotted. For example, moments of sojourning may accentuate personal self-reflection and perspective as necessary processes toward mending disruption, while moments of disordering may demand what Michael Ignatieff (1988) called an "ethic of ironic struggle" (p. 33), a resigned confrontation with the contingencies, absurdities, and mysteries of life during illness.

In a parallel way, caregivers may gain a sense of the extent to which self-authorship is important to their patients by how they construct agentivity; preferences for patient identities often suggest that agency is entrusted to those who are treating the disease, while use of warrior, advocate, or athlete identities tend to signify desires for personal control over one's own healing. Caregivers may use knowledge of these different languages of self and the needs they represent to design a personally relevant course of treatment and support. Application of these representations need not pigeonhole patients' narratives into essentialized plots or identities; therapeutic emplotment is forever a dynamic and 'momentary' process, a negotiation requiring sensitivity to its own evolution over time. For localized moments of meaning and (non)being there can only be localized conclusions and solutions.

Limitations and Recommendations

In this final section to my dissertation, I provide a few notable limitations to my interpretations of the narratives followed by propositions for future research to improve or expand upon my study. I categorized these limitations into three sets of issues: 1) narrative truths and inventions, 2) Underrepresented and self-selected voices, and 3) the participant-researcher relationship¹.

1. Narrative Truths and Inventions

Recall the words of the Personal Narratives Group (1989): "when talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they *are* revealing truths" (p. 261; original text). In the previous chapter, I expressed concern over the dangers of allowing these truths to grow beyond their specificity precisely because they conceal other possible truths at the same time as revealing important details about life with

¹ These may also be seen, from a social constructionist perspective, as the conditions of possibility for understanding others' stories. As such, these limitations may be argued to be necessary and unavoidable.

cancer. In the words of deconstructionist Ed Heide (1991), narratives often do “violence” to the complexities of truth in their impositions of order and coherence (p. 222). No matter how carefully we try to tease out the merits of narratives, we are continually confronted with their potential to deceive and distort.

The young adults’ narratives must be tempered by this consideration. They were retrospective accounts of events, sometimes from many years ago, and therefore subject to inventions of memory. This is the other side to the “innovation” involved in personal narratives (Ricoeur, 1984, p. 68); people may take creative licence to tell their stories in easily digestible, self-enhancing, or duplicitous ways to serve their current needs. The entangled desires and politics implicit in the young adults’ stories make them suspect to any conclusions I make about their ‘genuine’ needs and experiences. That said, I typically took these considerations into account and, as a result, the extent to which I contextualized their stories was somewhat at odds with how they understood themselves and their illnesses.

Let me provide an example to make this point clearer. Many of the interviewees positioned themselves as “universal subjects” or as a member of the transcultural category ‘humanity’ (Smith, 1993, p. 154-155) when, in fact, they were situated in particular social, cultural, and political locations. For instance, when I asked questions about their ethnicity, they often received the questions with perplexity, as though the questions were odd or irrelevant in contexts of illness experiences. Furthermore, in the aforementioned moments of community with other cancer patients, “cancer” was talked about as a singular, general disease, glossing over its plural forms, meanings, and effects. When subject and disease get displayed as universal (or historically neutral), they can have widespread positive effects; for instance, they may resonate

with many people and lead to united social efforts such as AYA task forces in Canada, the United Kingdom, and the United States.

But, they also blur important distinctions and divisions in experiences, hide biases and assumptions, and make moral claims that cannot and should not be applied to others' experiences. This can lead to a misguided assumption, "If I can do it, so can you," that is naïve of difference: between persons, life circumstances, cancers, cultures, socioeconomic statuses, health access, etc. If we professional readers treat each person as a "universal subject" with a "universal truth," we are at a loss with how to support contradictory universal truths. By treating truth as plural and locally situated, my reading and reproduction of their stories neutralized the dangers of their more dogmatic expressions, but in the process cooled some of the fervor with which they affirmed their views.

In sum, the potential for narrative truths and narrative deceptions continues to hang over my head, holding me back from taking a strong stance on the certainty of my conclusions. The methodology of narrative analysis is forever burdened by this limitation. My remedy (or, more accurately, my consolation) throughout this project was to place personal narratives against the backdrops of their narrative environments, thereby situating their truths/inventions within local spaces of experience and horizons of expectation.

Perhaps these limitations could be properly addressed through future mixed method research on young adult cancer. Especially fruitful would be participant observation methods—as are common in ethnographic research—as people go in for treatment and, later, for follow-up appointments. This would, among other things, enable researchers to see the many ways in which meaning and being are constructed in everyday life, possibly broadening our understanding of the existential challenges of illness. Furthermore, researchers would be able to

get a look at numerous intersubjectivities at work (e.g., clinical relationships) and perhaps gain a better understanding of the negotiative exchanges between young adults and those around them. In terms of acquiring an even richer representation of young adult life with cancer, going beyond interview and narrative techniques seems to be the next step.

2. Underrepresented and Self-Selected Voices

The second limitation of the study has to do with who was involved in the study. On the one hand, I could not have asked for a more diverse group of individuals. They lived across Canada, from the East to West Coasts, and ranged in age from late teens to early forties. I had more representation of men than most other samples of young adults. They lived with an array of forms of cancer, diagnosed from Stages 0 to 4, and for quite different periods of time.

On the other hand, the sample was composed of particular ‘clusters’ of people. Nearly all were Caucasian and middle-class individuals, which illuminates a selection of cancer experiences from certain perspectives. I did not encounter experiences tied more specifically to racial and ethnic minorities, for example, such as discrimination or racial tensions within healthcare systems, or engagement with dominant discourses of meaning, self, and morality outside of a North American context.

In addition, some demographics were relatively more represented than others, possibly producing a skewed representation of the whole sample’s experiences and concerns. Perhaps the most significant of these is the fact that Saskatchewan and Ontario residents are overrepresented, while half the provinces and territories had no representation; this limitation is particularly important because provincial differences in healthcare quality and coverage may lead to very different experiences of treatment across the country. Also, two-thirds of the participants had not passed the 5-year mark since diagnosis, which I noted as a significant milestone for many

patients. Perhaps the extent of uncertainty, liminality, and chaos within the narratives has to do with being ‘behind the finish line’ and lacking the temporal distance that may be needed to put life disruptions into a more orderly account. I do believe this to some extent, although the chronicity of existential challenges people a decade out of treatment suggests time does not always unify experiences.

My participants were, for the most part, rather comfortable sharing their stories with me, even some of the more difficult moments of their lives. Not anything to complain over, this level of comfort does distinguish them from many other people with cancer who are not at ease talking about their experiences, do not have the time to join a study, or struggle to compose an ‘account’ of life with cancer. In fact, despite the variety of narratives I encountered in my research, many (kinds of) stories were out of reach: the stories left untold or edited out by my participants, the stories of people who cannot or chose not to voice their experiences, and the stories of those who have died. The narratives I heard were self-selected by a minority of cancer patients who seek out more public avenues for disseminating their stories, like research projects, media interviews and releases, online forums, etc.

A final but significant concern regarding the participants is their involvement in each others’ discourses. The majority of participants were deeply connected to young adult cancer patient communities and familiar with their rhetoric. It is difficult to know how much contact each person had, as well as its effects on how they told their own stories; for example, two people (i.e., Tim and Dani from ch. 4) from very different areas of the country and with different levels of interactions with other young adults held very similar ideas about returning to normal in post-treatment. Nevertheless, it is quite likely that perceptions of young adult cancer patients as a

‘community,’ as a distinct group of people with shared needs, solidified with extended correspondence with one another.

I recall a story from Ron, a Hodgkin’s lymphoma patient in his late twenties; told when the tape recorder was turned off, the story referred to a young man at a support group who said he didn’t even know he was a young adult with distinct needs until he had attended their meetings, that is, from a critical perspective, until he had entered into their discourse and was shaped by it. As mentioned in chapter 5, communal identities may provide a safe haven for existential questions and answers where few others exist, and one danger they bear as a result is breeding ideological constructions of meaning and being. Thus, I face the possibility that shared themes across the participants’ narratives were little more than artifacts of their indoctrination into the rhetoric of their cancer communities.

Small samples tend to suffer for their lack of diversity. The voices in my chapters were representative of select cancer experiences, life circumstances, and narrative preferences, to the neglect of any number of other silenced or marginalized voices. The purpose of my study was ambitious to the extent of including as many perspectives as I could given the restraints of time, sample size, and volunteer participation.

Future studies could employ several different strategies to improve on this research. People of lower socioeconomic status and ethnic minorities continue to be underrepresented in cancer discourses and may benefit from more targeted studies in search of their voices². With regard to the issue of temporal distance from diagnosis and treatment, a longitudinal study of young adults’ narratives from diagnosis to the 5-year mark (and beyond) may help us to answer a number of important questions: (How) does the liminality and chronicity of cancer change over

² My postdoctoral research on the experiences of cancer survivorship among First Nations, Inuit, and Métis peoples will be an attempt to address some of these limitations.

time? Do cancer narratives become more orderly over the passage of time? (How) do horizons of expectation change as people live more than 5 years beyond their diagnosis? Finally, I was graciously invited to work with several cancer communities while I recruited participants; because they seemed to be crucial sources of support and guidance for the young adults, they could be the subject of future psychosocial research, including the discourses formed, resisted, and negotiated within their spaces.

3. The Participant-Researcher Relationship: A Fourth Intersubjective Negotiation

In chapter 5 I discussed three important intersubjectivities in the young adult narratives: clinical relationships, local worlds, and cancer communities. My analyses must be considered in light of another intersubjectivity, between each participant and me within the interview space. Physician Rita Charon (2006) believed that, alongside narrative forms, identities, and ethics, the relationships between narrators and audiences are primary features of stories; according to her, the meaning of a narrative “arises from and is created by the meeting between teller and listener” (p. 52). The influences their situational telling had on the young adults’ narratives can be gleaned from exchanges that appeared to be negotiations between the participant’s and my horizons.

Because of the self-reflection demanded of this analysis it is difficult even to begin, but I find inspiration in the work of French journalist and writer Emmanuel Carrère. He wrote a touching account in *Lives other than my own* (2011) of the deep sense of loss felt by family and friends as his sister-in-law, Juliette, passed away from advanced cancer. Part biographical and part autobiographical, Carrère sensitively explored the distance between those most affected by loss and the people on the periphery of their anguish. He once said to Etienne, a dear colleague of Juliette’s and former cancer patient, “I didn’t know Juliette, I have no place mourning her, nothing authorizes me to write about this”; in response, Etienne said, “That’s what *gives* you the

authority, and in a way it's the same for me. Her illness wasn't my illness...I was facing her, near her, but in my place" (p. 218; original text). Both men's words resonate with me: doubting whether I did justice to the young adults' complex stories, and at the same time knowing that the distance between our lives enabled me to critically engage with the larger contexts of their stories.

Bringing my horizons of expectation—my pursuit of a “pluralizing hermeneutics” (Marquard, 1981/1989)—into the interviews produced moments of collaboration as well as moments of dispute. As an example of the former, when controversial or non-medical causal ontologies emerged (e.g., in the previous chapter, Jeanine implicating her former lover in the emergence of cervical cancer), I was respectfully attentive and invited elaboration on them. More frequently, when the young adults talked about death, fears of recurrence, or what their loved ones dubbed ‘negativity’—typically *mystery* or *chaotic narratives* that tend to gain less recognition than more redemptive or ‘positive’ narratives—I verbally legitimated these moments of meaning, believing they deserve more attention and validation.

On the other hand, there were times of tension when I cultivated the critical side of my enquiries. For example, I would try to contextualize certain dogmatic or generalized statements like “everything happens for a reason” by asking, “what does that mean?” Never asked in an offensive or combative way, still these questions sometimes put interviewees on the defensive, having to justify statements that, in their local social contexts, would likely be received without comment or contention. During these exchanges, my hermeneutics of suspicion stood out, perhaps making participants more cautious about what they said next. It is not that I explicitly encouraged any one moment of meaning or (non)being, even though I have my own personal

inclinations³; rather, I took an approach of enquiring further into brief but rich metaphors that came out unexpectedly—like cancer is a “monster” or a “gift”—in order to facilitate expansion on these packed “kernels” of meaning and plot (Teucher, 2003).

Any teller-listener relationship involves tensions between different spaces of experience and horizons of expectation—a dialectic between seeing others’ lives *as* other and seeing them as one’s own (Ricoeur, 1976, p. 43)—but they may redouble when moral explanations of illness are on the line. Emmanuel Carrère (2011), for instance, observed that he was “walking on eggshells” when talking about etiology with Etienne. He wrote about the difficulty in respecting that Etienne “refuses all psychosomatic interpretations of his disease” while, at the same time within himself, feeling that “cancer is not a disease that hits you from outside, by accident (not always, anyway, and not necessarily)” (p. 107-108). Putting these tensions on the page was his way of honouring Etienne’s steadfast perceptions of his illness while still delicately providing his hermeneutics of suspicion. I may have been less forthright than Carrère in sharing my personal opinions of cancer’s origins, but I worked toward juxtaposing different perspectives without placing one on a higher pedestal.

Discussing the young adults’ stories in terms of ‘moments’ is itself a critical language, in a sense, a foreign language to the young adults, a language brought into the co-construction of their narratives through my horizons of understanding. I could not talk about their narratives outside of their ‘*partial* translation’⁴ into my discourse, thereby erasing some of what made their narratives ‘other’ to my understanding. Let me include a brief example. Several of the young

³ For example, I tend to side with Rimmon-Kenan (2002) and others who suggest that *chaotic* experiences are often unjustly marginalized, and that the popularity of *recovery narratives* is possibly due to the social pressures to tell happy endings. Furthermore, I harbour slightly more suspicion toward *battle* metaphors, particularly when deaths are judgmentally constructed as ‘lost fights.’ That said, I have become much less certain of my biases as a result of studying young adults who found value and direction in these moments of meaning and being.

⁴ I argue it is partial because I employed the young adults’ own words and statements whenever possible.

adults said that they were telling me feelings, thoughts, and stories that no one else had heard before—including their spouses, closest friends, and families. Though I admit a certain pride in being told they were entrusting me with their most private, ‘untold,’ narratives, I received those claims with some skepticism. Maybe they marked privileged access to the young adults’ mental meanings, or perhaps they marked a sly ploy to let down my guard of critical thinking. From my perspective, they signified a change in the social contexts of the young adults’ expressed meanings. Their comments made me aware that the intersubjectivity between us *differed* from other intersubjectivities affecting their stories. I was told *different* stories, not necessarily truer or more authentic stories.

I could not always say *how* they differed, though I did sometimes have access to stories told to other audiences (e.g., in blogs). When I could compare, the tone almost always seemed somewhat lighter, more optimistic, and more situated within *narratives of recovery* than in the interviews. These ‘other’ stories were still rich with expressions of meaning and (non)being, but more chaotic *moments of disordering* and *moments of non-being* were certainly fewer and less prominent, giving credence to the young adults’ statements about being expected to tell more coherent and redemptive narratives. Within a research context, with a ‘stranger’ and advertised Psychology graduate (which alone may have sparked all sorts of expectations), slightly different, less publicly familiar narratives may have been performed.

The participant-researcher relationship can shape stories in a variety of different ways; I have tried to portray how horizons of expectation lead us down different paths than may have been taken in the meeting of other horizons at different times and contexts. Because of the influences of the research context, and the other intersubjectivities discussed above, it seems a dubious venture to assume the young adults’ narratives were entirely ‘their own.’ Though

creative in their construction, the narratives were partially shaped by the characters within them and the audiences responding to them.

For future research I would recommend only more reflexivity on the researcher's role in negotiating meaning and being. I would not suggest possible ways of removing the influence of the researcher from the stories produced by participants. It is certainly a limitation on the conclusions we can make (especially when our questions are leading), but from another perspective it is a condition for the possibility of narration. People's stories somewhat depend on their audiences, as they are tailored to the situation of their telling. Different stories may be produced for different audiences, but each telling contributes in a larger way to the many possible meanings people hold to their lives while wandering the endless paths of chronic illness.

References

- Albom, M. (1997). *Tuesdays with Morrie: An old man, a young man, and life's greatest lesson*. New York, NY: Doubleday.
- Alschuler, L. & Gazella, K. (2010). *The definitive guide to cancer: An integrative approach to prevention, treatment, and healing* (3rd edition). Berkeley, CA: Celestial Arts.
- Aristotle. (1987). *Poetics*. (R. Janko, Trans.). Indianapolis, IN: Hackett. (Original work written 335 B.C.).
- Arnett, J. (1999). Adolescent storm and stress, reconsidered, *American Psychologist*, 54(3), 317-326.
- . (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480.
- . (2002). The psychology of globalization, *American Psychologist*, 57(10), 774-783.
- . (2011). Chapter 12: Emerging adulthood(s): The cultural psychology of a new life stage. In L. Arnett Jensen (Ed.), *Bridging cultural and developmental approaches to psychology* (pp. 255-275). Oxford, UK: Oxford University Press.
- Attig, T. (2001). Relearning the world: Making and finding meanings. In R. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 33-53). Washington, DC: American Psychological Association.
- Audi, R. (Ed.). (1999). *Cambridge dictionary of philosophy*. Cambridge, UK: Cambridge University Press.
- Baddeley, J., & Singer, J. (2007). Charting the life story's path: Narrative identity across the life span. In D.J. Clandinin (Ed.), *Handbook of narrative inquiry: Mapping a methodology* (pp. 177-202). Thousand Oaks, CA: Sage.

- Baldwin, J. (Ed.). (1957). *Dictionary of philosophy and psychology* (Vol. 1). New York, NY: P. Smith.
- Banks, J., & Prior, L. (2001). Doing things with illness: the micro-politics of the CFS clinic, *Social Science and Medicine*, 52, 11-23.
- Barr, R. (2011). Adolescents, young adult, and cancer—the international challenge, *Cancer*, 117(Suppl. 10), 2245-2249.
- Barr, R., Rogers, P., & Schacter, B. (2011). Commentary: Preamble, *Cancer*, 117(Suppl. 10), 2239-2240.
- Barthes, R. (2000). Introduction to the structural analysis of narratives. In M. Mcquillan (Ed.), *The narrative reader* (pp. 109-114). (S. Heath, Trans.). London, UK: Routledge. (Original work published 1966).
- Becker, E. (1973). *The denial of death*. New York, NY: The Free Press.
- Becker, G. (1997). *Disrupted lives: How people create meaning in a chaotic world*. Berkeley and Los Angeles, CA: University of California Press.
- Bell, K. (2010). Cancer survivorship, mor(t)ality and lifestyle discourses on cancer prevention, *Sociology of Health and Illness*, 32(3), 349-364.
- Benjamin, W. (2000). The storyteller: Reflections on the works of Nikolai Leskov. In M. Mcquillan (Ed.), *The narrative reader* (pp. 46-53). (H. Zohn, Trans.). London, UK: Routledge. (Original work published 1955).
- Blackburn, S. (2005). *Oxford dictionary of philosophy*. Oxford, UK: Oxford University Press.
- Blank, T., & Bellizzi, K. (2008). A gerontologic perspective on cancer and aging, *Cancer*, 112 (11), 2569-2576.

- Bleyer, A., Barr, R., Hayes-Lattin, B., Thomas, D., Ellis, D., & Anderson, B. (2008). The distinctive biology of cancer in adolescents and young adults, *Nature Reviews Cancer*, 8, 288-298.
- Blinderman, C.D. & Cherny, N.I. (2005). Existential issues do not necessarily result in existential suffering: Lessons from cancer patients in Israel, *Palliative Medicine*, 19, 371-380.
- Bolmsjö, I. (2000). Existential issues in palliative care—interviews with cancer patients. *Journal of Palliative Care*, 16(2), 20-24.
- . (2002). Meeting existential needs in palliative care—who, when, and why? *Journal of Palliative Care*, 18(3), 185-191.
- Breitbart, W., Gibson, C., Poppito, S., & Berg, A. (2004). Psychotherapeutic interventions at the end of life: A focus on meaning and spirituality, *Canadian Journal of Psychiatry*, 49, 366-372.
- Breitbart, W., & Heller, K. (2003). Reframing hope: Meaning-centred care for patients near the end of life, *Journal of Palliative Medicine*, 6(6), 979-988.
- Bronfen, E. (2000). Spectral stories. In M. Mcquillan (Ed.), *The narrative reader* (pp. 192-197). London, UK: Routledge. (Original work published 1992).
- Broyard, A. (1992). *Intoxicated by my illness*. New York, NY: Fawcett Columbine.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, UK: Harvard University Press.
- . (1990). *Acts of meaning*. Cambridge, UK: Harvard University Press.
- Buckman, R. (2006). *Cancer is a word, not a sentence*. Toronto, Canada: Key Porter Books.
- Burgess, A. (1962). *A clockwork orange*. London, UK: Penguin Books.
- Burman, E. (2008). *Deconstructing developmental psychology*. London, UK: Routledge.

- Bury, M. (1982). Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4(2), 167-182.
- Butler, J. (2004). *Undoing gender*. New York, NY: Routledge.
- Camus, A. (1946). *The stranger*. (S. Gilbert, Trans.). New York, NY: Vintage Books. (Original work published 1942).
- Cancer Care Ontario. (2006). *Cancer in young adults in Canada*. Retrieved from the CCO website on June 12, 2013 <http://www.cancercare.on.ca>.
- Canadian Cancer Society. (2009). *Canadian cancer statistics 2009*. Toronto, Canada: Canadian Cancer Society.
- . (2012). *Canadian cancer statistics 2012*. Toronto, Canada: Canadian Cancer Society.
- . (2013). *Canadian cancer statistics 2013*. Toronto, Canada: Canadian Cancer Society.
- Canadian Institute of Health Research. (2009). *Paediatric/adolescent/young adult cancer: A pan-Canadian initiative*. Ottawa: Retrieved on the CIHR website on July 29, 2013: <http://www.cihr-irsc.gc.ca/e/40559.html>.
- Canadian Partnership Against Cancer, (2010). *Cancer in adolescents and young adults (15-29 years): Fact sheet*. Retrieved from the CPAC website on June 12, 2013 <http://www.partnershipagaincancer.ca/2010/03/11/cancer-in-adolescents-and-young-adults-15-29-years/>.
- Carr, D. (1986). *Time, narrative, and history*. Bloomington and Indianapolis, IN: Indiana University Press.
- Carr, K. (2007). *Crazy sexy cancer tips*. Guilford, CT: Globe Pequot Press.
- Carel, H. (2008). *Illness*. Stocksfield, UK: Acumen.
- Carrère, E. (2011). *Lives other than my own* (L. Coverdale, Trans.). New York, NY: Metropolitan Books. (Original work published 2009).

- Carrick, R. (2013). Young adults really do have it tougher. *The Globe and Mail*, March 25, 2013.
- Cart, M. (2011). *Young adult literature: From romance to realism*. American Library Association.
- Carter, H., MacLeod, R., Brander, P., and McPherson, K. (2004). Living with a terminal illness: Patients' priorities, *Advanced Nursing*, 45(6), 611-620.
- Cella, D., & Tross, S. (1986). Psychological adjustment to survival from Hodgkin's disease, *Journal of Consulting & Clinical Psychology*, 54, 616-622.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: A qualitative study, *British Medical Journal*, 328, 1470-1474.
- Charne, S. (1984). *Meaning and myth in the study of lives: A Sartrean perspective*. Philadelphia, PA: University of Pennsylvania Press.
- Charmaz, K. (1992). *Good days, bad days*. Chapel Hill, NC: Rutgers University Press.
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. New York, NY: Oxford University Press.
- Chouinard, V. (1994). Geography, law and legal struggles: Which ways ahead? *Progress in Human Geography*, 18(4), 415-440.
- Clausen, M. (2010). *Fateful embrace: Lived body and identity among young adults with cancer*. Ann Arbor, MI: UMI Dissertation Publishing.
- Clarke, J., & James, S. (2003). The radicalized self: The impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome, *Social Science and Medicine*, 57, 1387-1395.
- Coates, K., & Morrison, B. (2012). The uses and abuses of university: Canada's post-secondary education system is failing our students, and our economy. *The Walrus Magazine*, September 24, 2012.

- Cohn, S. (1999). Taking time to smell the roses: accounts of people with chronic fatigue syndrome and their struggle for legitimization, *Anthropology and Medicine*, 6(2), 195-215.
- Cole, M. (2006). Culture and cognitive development in phylogenetic, historical, and ontogenetic perspective. In W. Damon and R. M. Lerner (Eds.), *Handbook of child psychology* (Vol. 2, pp. 636-683). Hoboken, NJ: Wiley.
- Corrigan, K. (2008). *The middle place*. New York, NY: Hyperion.
- Coupland, D. (1991). *Generation X: Tales for an accelerated culture*. New York, NY: St. Martin's Press.
- Couser, G.T. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison, WI: University of Wisconsin Press.
- . (2005). Genre matters: Form, force, and filiation, *Life Writing*, 2(2), 139-156.
- Coward, D. (1997). Constructing meaning from the experience of cancer, *Seminars in Oncology Nursing*, 13(4), 248-251.
- Crawshaw, M.A., Glaser, A.W., Hale, J.P., & Sloper, P. (2009). Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years, *European Journal of Cancer Care*, 18, 381-390.
- Crotty, M. (2003). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage.
- Csordas, T. (1994). Embodiment as a paradigm for anthropology, *Ethos*, 18(1), 5-47.
- D'Agostino, N., Penney, A., and Zebrack, B. (2011). Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors, *Cancer*, 117(Suppl. 10), 2329-34.

- De Beauvoir, S. (1983). *A very easy death*. (P. O'Brian, Trans.). Great Britain: Penguin Books.
(Original work published 1964).
- De Munck, V. (2000). What (or who) is the self? In *Culture, self, and meaning*, (pp. 31-59).
Prospect Height, IL: Waveland.
- Decker, C. (2006). Coping in adolescents with cancer: A review of the literature, *Journal of Psychosocial Oncology*, 24(4), 123-140.
- Decker, C., Haase, J., & Bell, C. (2007). Uncertainty in adolescents and young adults with cancer, *Oncology Nursing Forum*, 34(3), 681-688.
- Delvecchio-Good, M.J., Good, B., Schaffer, C., & Lind, S. (1990). American oncology and the discourse of hope, *Culture, Medicine and Psychiatry*, 14, 59-79.
- Derrida, J. (1976). *Of grammatology*. (G.C. Spivak, Trans.). Baltimore, MD: John Hopkins University Press. (Original work published 1967).
- . (2000). The law of genre. In M. Mcquillan (Ed.), *The narrative reader* (pp. 220-227). New York, NY: Taylor and Francis. (Original work published 1980).
- Devaney, J. (2012). *My leaky body: Tales from the gurney*. Fredericton, Canada: Goose Lane.
- Dexter, G. (2008). *Why not Catch-21? The stories behind the titles*. London, UK: Francis Lincoln.
- Diamond, L. (1998). Development of sexual orientation among adolescent and young adult women, *Developmental Psychology*, 34(5), 1085-1095.
- Dowling, S., Manthorpe, J., and Cowley, S. (2006). *Person-centred planning in social care: A scoping review*. London, UK: Kings College.
- Dumit, J. (2006). Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses, *Social Science and Medicine*, 62, 577-590.

- Dunn, J., & Steginga, S. (2000). Young women's experience of breast cancer: defining young and identifying concerns, *Psycho-Oncology*, 9, 137-146.
- Eagleton, T. (2007). *The meaning of life: A very short introduction*. Oxford, UK: Oxford University Press.
- Egan, S. (1999). *Mirror talk: Genres of crisis in contemporary autobiography*. Chapel Hill: University of North Carolina Press.
- Engelke, M., & Tomlinson, M. (2006). Meaning, anthropology, Christianity. In M. Engelke & M. Tomlinson (Eds.), *The limits of meaning: Case studies in the anthropology of Christianity* (pp. 1-37). New York, NY: Beghahn Books.
- Erikson, E. (1968). *Identity, youth, and crisis*. New York, NY: W.W. Norton and Company.
- . (1980). *Identity and the life cycle*. New York, NY: W.W. Norton and Company.
- Ettinger, R., & Heiney, S. (1993). Cancer in adolescents and young adults: Psychosocial concerns, coping strategies, and interventions, *Cancer*, 71(Suppl. 10), 3276-3280.
- Feinberg, L. (2012). *Moving toward person- and family-centred care*. Washington, DC: American Association of Retired Persons.
- Fife, B. L. (2005). The role of constructed meaning in adaptation to the onset of life-threatening illness, *Social Science and Medicine*, 61, 2132-2143.
- Fischhoff, S., Antonio, J., & Lewis, D. (1998). Favorite films and film genres as a function of race, age, and gender. *Journal of Media Psychology*, 3(1), 1-9.
- Forster, E.M. (2000). 'The story' and 'the plot'. In M. Mcquillan (Ed.), *The narrative reader* (pp. 44-46). London, UK: Routledge. (Original work published 1963).
- Foucault, M. (1978). *The history of sexuality: An introduction* (Vol. 1). (R. Hurley, Trans.). New York, NY: Vintage Books. (Original work published 1976).

- . (1990.). *The history of sexuality: The use of pleasure* (Vol. 2). (R. Hurley, Trans.). New York: Vintage Books. (Original work published 1984).
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.
- Frank, A. (2010). Tricksters and truth tellers: Narrating illness in an age of authenticity and appropriation, *Literature and Medicine*, 28(2), 185-199.
- Frankl, V. (1984). *Man's search for meaning*. (I. Lasch, Trans.). New York, NY: Pocket Books. (Original work published 1946).
- Freeman, M. (2007). Performing the event of understanding in hermeneutic conversations with narrative texts, *Qualitative Inquiry*, 13(7), 925-944.
- Freeman, M.P. (2010a). Afterword: 'Even amidst': Rethinking narrative coherence. In M. Hyvarinen, L-C. Hyden, M. Saarenheimo, and M. Tamboukou (Eds.), *Beyond narrative coherence* (pp. 167-186). Amsterdam, Netherlands: John Benjamin.
- . (2010b). *Hindsight: The promise and peril of looking backward*. New York, NY: Oxford University Press.
- Friedan, B. (1994). *The fountain of age*. New York, NY: Simon and Schuster.
- Freud, S. (2011). *Beyond the pleasure principle*. (G. Richter, Trans.). Peterborough, Canada: Broadview. (Original work published 1920).
- Furstenberg, F. (2010). On a new schedule: Transitions to adulthood and family change, *The Future of Children*, 20(1), 67-87.
- Gadamer, H-G. (1989). *Truth and method* (2nd edition). (J. Weinsheimer and D. Marshall, Trans.). New York, NY: Continuum. (Original work published 1960).
- Gafni, A. (2011). Treatment of cancer in adolescents and young adults: Is affordability a concern? *Cancer*, 117(Suppl. 10), 2258-2261.

- Gamut, L. T. F. (1991). *Logic, language, and meaning: Introduction to logic* (Vol. 1). Chicago, IL: University of Chicago Press. (Original work published 1982).
- Garden, R. (2012). Telling stories about illness and disability: The limits and lessons of narrative, *Perspectives in Biology and Medicine*, 53(1), 121-135.
- Gavaghan, M.P., & Roach, J.E. (1987). Ego identity development of adolescents with cancer, *Journal of Pediatric Psychology*, 12(2), 203-213.
- Geertz, G. (1973). *The interpretation of cultures*. New York, NY: Basic Books.
- . (1986). Making experience, authoring selves. In V. Turner & E. Bruner (Eds.), *The anthropology of experience* (pp. 373-380). Urbana and Chicago, IL: University of Illinois Press.
- Gendlin, E. (1997). *Experiencing and the creation of meaning: a philosophical and psychological approach to the subjective*. Evanston, IL: Northwestern University Press.
- Gergen, M., & Gergen, K. (2007). Narratives in action. In M. Bamberg (Ed.), *Narrative: State of the art* (pp. 133-143). Philadelphia, PA: John Benjamins.
- Gillespie, R. (2000). When no means no: disbelief, disregard and deviance as discourses of voluntary childlessness, *Women's Studies International Forum*, 23(2), 223-234.
- Good, B. (1994). *Medicine, rationality, and experience: An anthropological perspective*. Cambridge, UK: Cambridge University Press.
- Good, B., & Delvecchio-Good, M. (1994). In the subjunctive mode: Epilepsy narratives in Turkey, *Social Science and Medicine*, 38(6), 835-842.
- Gough, A. (2005). Body/mine: A chaos narrative of cyborg subjectivities and liminal experiences, *Women's Studies: An Interdisciplinary Journal*, 34(3-4), 249-264.
- Green, J. (2012). *The fault in our stars*. New York, NY: Dutton Books.

- Griffiths, C., Norton, L., Wagstaff, G., & Brunas-Wagstaff, J. (2002). Existential concerns in late stage cancer, *European Journal of Oncology Nursing* 6(4), 243-246.
- Grinyer, A. (2007). The biographical impact of teenage and adolescent cancer, *Chronic Illness*, 3, 265-277.
- . (2009). *Life after cancer in adolescence and young adulthood: The experience of survivorship*. London, UK: Routledge.
- Grinyer, A., & Thomas, C. (2004). The importance of place of death in young adults with terminal cancer. *Mortality*, 9(2), 114-131.
- Grossman, L. (2012). Top 10 fiction books. *TIME Magazine*, December 4, 2012.
- Gullette, M. (2004). *Aged by culture*. Chicago, IL: University of Chicago Press.
- Habermas, J., & Bluck, S. (2000). Getting a life: The emergence of the life story in adolescence, *Psychological Bulletin*, 126(5), 748-769.
- Halldorsdottir, S., & Hamrin, E. (1996). Experiencing existential changes: The lived experience of having cancer, *Cancer Nursing*, 19(1), 29-36.
- Hammond, C., Teucher, U., Duggleby, W., & Thomas, R. (2012). An “unholy alliance” of existential proportions: Negotiating discourses with men’s experiences of cancer and aging. *Journal of Aging Studies*, 26, 149-161.
- Handler, E. (1996). *Time on fire: My comedy of terrors*. London, UK: Souvenir Press.
- Hanisch, C. (1970). The personal is political. In S. Firestone & A. Koedt (Eds.), *Notes from the second year: Women’s liberation, major writings of the Radical Feminists* (pp. 76-78). New York, NY: Radical Feminism.
- Harris, G. (1989). Mechanism and morality in patients’ views of illness and injury, *Medical Anthropology Quarterly*, 3(1), 3-21.

- Harrison, M. (2000). From medical astrology to medical astronomy: solar and planetary theories of disease in British medicine, c. 1700–1850, *The British Journal for the History of Science*, 33(1), 25-48.
- Havighurst, R. (1972). *Developmental tasks and education*. Philadelphia, PA: D. McKay.
- Heidegger, M. (1962). *Being and time*. (J. Macquarrie & E. Robinson, Trans.). San Francisco, CA: HarperCollins. (Original work published 1927).
- . (2001). *The Zollikon seminars*. (R. Askay & F. Mayr, Trans.). Evanston, IL: Northwestern University Press. (Original work published 1987).
- Heidt, E. (1991). Conclusion: A philosophy of autobiographical writing: A metaphysics of presence. In *Vision voiced: Narrative viewpoint in autobiographical writing* (pp. 219-238). New York, NY: Peter Lang.
- Heilbrun, C. (1988). *Writing a woman's life*. New York, NY: Bellantine Books.
- Henoch, I., & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: an integrative literature review, *Psycho-Oncology*, 18(3), 225-236.
- Henig, R. (2010). What is it about 20-somethings? *New York Times*, 20.
- Henig, R., & Henig, S. (2012). *Twenty something: Why do young adults seem stuck*, New York, NY: Hudson Street Press.
- Howe, N., & Strauss, W. (2000). *Millenials rising: The next great generation*. New York, NY: Vintage Books.
- Hunsaker-Hawkins, A. (1993). *Reconstructing illness: Studies in pathography*. West Lafayette, IN: Purdue University Press.
- Hunt, L. (1998). Moral reasoning and the meaning of cancer: Causal explanations of oncologists and patients in Southern Mexico, *Medical Anthropology Quarterly*, 12(3), 298-318.

Hunter, B. (2004). *Staying alive: Life-changing strategies for surviving cancer*. New York, NY: Doubleday.

Hyde, L. (1998). *Trickster makes this world*. New York, NY: Farrar, Straus, and Giroux.

Hyden, L-C. (1995). In search of an ending: Narrative reconstruction as a moral quest, *Journal of Narrative and Life History*, 5(1), 67-84.

Hyvarinen, M., Hyden, L-C., Saarenheimo, M., & Tamboukou, M. (2010). Chapter 1. In M. Hyvarinen, L-C. Hyden, M. Saarenheimo, & M. Tamboukou (Eds.), *Beyond narrative coherence* (pp. 1-15). Amsterdam, Netherlands: John Benjamins.

Ignatieff, M. (1988). Modern dying, *The New Republic*, 199(26), 28–33.

Jackson, M. (2005). *Existential anthropology: Events, exigencies, and effects*. New York, NY, and Oxford, UK: Berghahn Books.

Jacobsen, B., Jørgensen, S.D., & Jørgensen S.E. (2000). The world of the cancer patient from an existential perspective, *Journal of the Society for Existential Analysis*, 11(1), 122-135.

Jain, S.L. (2007). Living in prognosis: Toward an elegiac politics, *Representations*, 98, 77-92.

Jenkins, J., & Valiente, M. (1994). Bodily transactions of the passions: *el calor* among Salvadoran women refugees. In T. Csordas (Ed.), *Embodiment and experience* (pp. 163-182). Cambridge, UK: Cambridge University Press.

Jureric, A. (2012). *Illness as narrative*. Pittsburg, PA: University of Pittsburg Press.

Kadar, M. (1992). Coming to terms – from genre to critical practice. In M. Kadar (Ed.), *Essays on life writing: From genre to critical practice* (pp. 3-16). Toronto, Canada: University of Toronto Press.

Kameny, R., & Bearison, D. (2002). Cancer narratives of adolescents and young adults: A quantitative and qualitative analysis, *Children's Health Care*, 31(2), 143-173.

- Katz, A. (2011). *Surviving after cancer: Living the new normal*. Lanham, MD: Rowman and Littlefield.
- Keller, P. (1999). *Husserl and Heidegger on human experience*. Cambridge, UK: Cambridge University Press.
- Kellerman, J., & Katz, E.R. (1977). The adolescent with cancer: Theoretical, clinical and research issues, *Journal of Pediatric Psychology*, 2(3), 127-131.
- Kelly, D., Pearce, S., & Mulhall, A. (2004). 'Being in the same boat': Ethnographic insights into an adolescent cancer unit, *International Journal of Nursing Studies*, 41, 847-857.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. Basic Books.
- . (2006). *What really matters: Living a moral life amidst uncertainty and danger*. New York, NY: Oxford University Press.
- Kleinman, A., & Benson, P. (2006). Anthropology in the clinic: The problem of cultural competency and how to fix it, *PLOS Medicine*, 3(10), 1673-1676.
- Kleinman, A., & Kleinman, J. (1991). Suffering and its professional transformation: Toward an ethnography of interpersonal experience, *Culture, Medicine and Psychiatry*, 15(3), 275-301.
- Klem, P., Miller, M.A., & Fernsler, J. (2000). Demands of illness in people treated for colorectal cancer, *Oncology Nursing Forum*, 27(4), 633-639.
- Kuhl, D. (2003). *What dying people want: Practical wisdom for the end of life*. Toronto, Canada: Doubleday Canada.
- Kyngas, H., Mikkonen, R., Mousiainen, E., Ryttilahti, M., Seppanen, P., Vattovaara, R., Jamsa, T., (2000). Coping with the onset of cancer: coping strategies and resources of young people with cancer, *European Journal of Cancer Care*, 10, 6-11.

- Lachman, M. (2004). Development in midlife, *Annual Review of Psychology*, 55, 305-331.
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. Chicago, IL: University of Chicago Press.
- Landmark, B., Strandmark, M., & Wahl, A. (2001). Living with newly diagnosed breast cancer—the meaning of existential issues, *Cancer Nursing*, 24(3), 220-226.
- Lazarus, R. (1998). The trivialization of distress. In *Fifty years of the research and theory of R.S. Lazarus: An analysis of historical and perennial issues* (pp. 251-271). Hillsdale, NJ: Lawrence Erlbaum.
- Lee, V. (2008). The existential plight of cancer: Meaning making as a concrete approach to the intangible search for meaning, *Support Care Cancer*, 16, 779-785.
- Leder, D. (1990). *The absent body*. Chicago, IL: University of Chicago Press.
- Lerner, M. (1991). *Wrestling with the angel: A memoir of my triumph over illness*. New York, NY: Simon and Schuster.
- Levinas, E. (2000). *God, death, and time*. (B. Bergo, Trans.). Stanford, CA: Stanford University Press. (Original work published 1993).
- Levinson, D. (1986). A conception of adult development, *American Psychologist*, 41(1), 3-13.
- Lifton, R.J. (1993). *The protean self: Human resilience in an age of fragmentation*. New York, NY: Basic Books.
- List, M., Ritter-Sterr, C., & Lansky, S.B. (1991). Cancer during adolescence, *Pediatrician*, 18(1), 32-36.
- Little, M., Jordens, C., Paul, K., Montgomery, K., & Philipson, B. (1998). Liminality: A major category of the experience of cancer illness, *Social Science and Medicine*, 47(10), 1485-1494.

- Little, M., Paul, K., Jordens, C., & Sayers, E-J. (2002). Survivorship and discourses of identity, *Psycho-Oncology*, *11*, 170-178.
- Lunau, K. (2012). Campus crisis: The broken generation: Why so many of our best and brightest students report feeling hopeless, depressed, even suicidal, *Maclean's Magazine*, September 5, 2012.
- Lyon, M., & Barbalet, J. (1994). Society's body: Emotion and the “somatization” of social theory. In T. Csordas (Ed.), *Embodiment and experience: The existential ground of culture and self* (pp. 48-66). Cambridge, UK: University of Cambridge Press.
- MacKenzie, C. (2008). Introduction. In C. MacKenzie & K. Atkin (Eds.), *Practical identity and narrative agency* (pp. 1-28). New York, NY, and London, UK: Routledge.
- Marcia, J. (1973). Ego-identity status: Relationship to change in self-esteem, ‘general maladjustment’, and authoritarianism. In M. Argyle (Ed.), *Social encounters: Contributions to social interaction* (pp. 340-354). Chicago, IL: Aldine.
- Marquard, O. (1989). *Farewell to matters of principle: Philosophical studies*. (R. Wallace, Trans.). New York, NY: Oxford University Press. (Original work published 1981).
- Matthews, C. (2007). *Reflections on the c-word: At the centre of the cancer labyrinth*. North Saanich, Canada: Hedgerow Press.
- Mattingly, C. (1998). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge, UK: Cambridge University Press.
- Mauss, M. (1985). *A category of human mind: The notion of person: The notion of self*. Cambridge, UK: Cambridge University Press.
- McAdams, D. (1993). *The stories we live by: Personal myths and the making of the self*. New York, NY: The Guilford Press.

- . (2006). *The redemptive self: Stories Americans live by*. New York, NY: Oxford University Press.
- . (2013). Life authorship: A psychological challenge for emerging adulthood, as illustrated in two notable case studies, *Emerging Adulthood*, 1(2), 151-158.
- McAdams, D., & Logan, R. (2004). Chapter 2: What is generativity? In E. De St. Aubin, D. McAdams, & T-C. Kim (Eds.), *The generative society: Caring for future generations* (pp. 15-31). Washington, DC: American Psychological Association.
- McDermott, R.P., & Varenne, H. (1996). Culture, development, disability. In R. Jessor, A. Colby, & R.A. Shweder (Eds.), *Ethnography and human development: Context and meaning in social enquiry* (pp. 101-126). Chicago, IL: University of Chicago Press.
- McGoldrick, D., Gordon, P., Whiteson, M., Adams, H., Rogers, P., & Sutcliffe, S. (2011). Awareness and advocacy for adolescents and young adults with cancer, *Cancer*, 117(Suppl. 10), 2311-2315.
- McKenzie, H., & Crouch, M. (2004). Discordant feelings in the lifeworld of cancer survivors, *health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine*, 8(2), 139-157.
- McLean, K., & Pratt, M. (2006). Life's little (and big) lessons: Identity statuses and meaning-making in the turning point narratives of emerging adults, *Developmental Psychology*, 42(4), 714-722.
- Mead, M. (1963). *Coming of age in Samoa*. New York, NY: Mentor Books.
- Mehl-Madrona, L. (2007). *Narrative medicine: The use of history and story in the healing process*. Rochester, VT: Bear and Company.
- Meinke, P. (2001). *Greatest hits 1964-2000*. Columbus, OH: Pudding House Publications.

- Merleau-Ponty, M. (2002). *The phenomenology of perception*. (K. Paul, Trans.). London, UK, and New York, NY: Routledge. (Original work published 1945).
- Middlebrook, C. (1998) *Seeing the crab: A memoir of dying before I do*. New York, NY: Anchor Books.
- Middlemiss, J. (2008). *What should I tell you? A mother's final words to her infant son*. Brechin, Scotland: Printmatters.
- Mishler, E.G. (1995). Models of narrative analysis: A typology, *Journal of Narrative and Life History*, 5(2), 87–123.
- Mitchell, D. (2004). *Cloud atlas*. London, UK: Sceptre.
- Moadel, A., Morgan, C., Fatone, A., Grennan, J., Carter, J., Laruffa, G., Skummy, A., & Dutcher, J. (1999). Seeking meaning and hope: self-reported spiritual and existential needs among an ethnically-diverse cancer patient population, *Psycho-Oncology*, 8, 378-385.
- Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (2000). An exploratory factor analysis of existential suffering in Japanese terminally ill cancer patients, *Psycho-Oncology*, 9, 164-168.
- Morris, D. (1998). *Illness and culture in the postmodern age*. Berkeley and Los Angeles, CA: University of California Press.
- Mosack, K., Abbott, M., Singer, M., Weeks, M., & Rohena, L. (2005). If I didn't have HIV, I'd be dead now: Illness narratives of drug users living with HIV/AIDS, *Qualitative Health Research*, 15, 586-605.
- Mount, B., Boston, P., & Cohen, S.R. (2007). Healing connections: On moving from suffering to a sense of well-being, *Journal of Pain and Symptom Management*, 33(4), 372-388.
- Mount, E. (1993). Can we talk? Contexts of meaning for interpreting illness, *The Journal of Medical Humanities*, 14(2), 51-65.

- Mumma, G., Mashberg, D., & Lesko, L. (1992). Long-term psychosexual adjustment of acute leukemia survivors: Impact of marrow transplantation versus conventional chemotherapy, *General Hospital Psychiatry, 14*, 43-55.
- Mundorf, N., & Brownell, W. (1990). Media preferences of older and young adults, *The Gerontologist, 30*(5), 685-691.
- Murphy, R. (1987). *The body silent*. New York, NY: W.W. Norton and Company.
- Nathan, P., Hayes-Lattin, B., Sisler, J., & Hudson, M. (2011). Critical issues in transition and survivorship for adolescents and young adults with cancers, *Cancer, 117*(Suppl. 10), 2335-2341.
- Neugarten, B. (1987). The changing meaning of age, *Psychology Today, 21*(5), 29-33.
- Neuman, S. (1992). Autobiography: From different poetics to a poetics of difference. In M. Kadar (Ed.), *Essays on life writing: From genre to critical practice*. Toronto, Canada: University of Toronto Press.
- Nisbett, R. (2003). *The geography of thought: How Asians and Westerners think differently--and why*. New York, NY: Free Press.
- O'Murchadha, F. (2003). Book review: Husserl and Heidegger on Human Experience, *Husserl Studies, 19*(1), 93-100.
- Odo, R., & Potter, C. (2009). Understanding the needs of young adult cancer survivors: A clinical perspective, *Oncology, 23*(11), 23-33.
- Ogden, C., & Richards, I.A. (1927). *The meaning of meaning: A study of the influence of language upon thought and of the science of symbolism*. London, UK: K. Paul, Trench, Trubner.
- Olney, J. (1998). *Memory and narrative: The weave of life-writing*. Chicago, IL: University of Chicago Press.

- Oliver, M. (1989). Disability and dependency: a creation of industrial societies. In L. Barton (Ed.), *Disability and dependence*. London, UK, and New York, NY: The Falmer Press.
- . (1999). Capitalism, disability, and ideology: a materialist critique of the normalization principle. In R. Flynn & R. Lemay (Eds.), *A quarter-century of normalization and social role valorization: Evolution and impact* (pp. 163-173). Ottawa, Canada: University of Ottawa Press.
- Orwell, G. (2004). *Nineteen eighty-four*. Fairfield, IA: 1st World Library. (Original work published 1949).
- Ots, T. (1994). The silenced body—the expressive Leib: On the dialectic of mind and life in Chinese cathartic healing. In T. Csordas (Ed.), *Embodiment and experience* (pp. 116-136). Cambridge, UK: Cambridge University Press.
- Overboe, J. (1999). 'Difference in itself': Validating disabled people's lived experience, *Body and Society*, 5(4), 17-29.
- Park, J. (2006). Chapter 1: Naming the unnameable. In *Buddhisms and deconstructions* (pp. 9-20). Oxford, UK: Rowman and Littlefield.
- Park, C., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, 1(2), 115-144.
- Personal Narratives Group. (1989). *Interpreting women's lives: Feminist theory and personal narratives*. Indianapolis, IN: Indiana University Press.
- Piccart-Gebhart, M. (2010). New developments in hormone receptor-positive disease, *The Oncologist*, 15(5), 18-28.
- Plato. (1956). The republic. In E.H. Warmington & P.G. Rouse (Eds.), *Great dialogues of Plato* (pp. 118-422). (W.H.D. Rouse, Trans.). New York, NY: The New American Library. (Original work written 380 B.C.).

- Polkinghorne, D. (1983). *Methodology for the human sciences: Systems of inquiry*. Albany: State University of New York Press.
- Prince, G. (2000). On narratology (past, present, future). In M. Mcquillan (Ed.), *The narrative reader* (p. 129). London, UK: Routledge. (Original work published 1990).
- Pritchard, S., Cuvulier, G., Harlos, M., & Barr, R. (2011). Palliative care in adolescents and young adults with cancer, *Cancer, 117*(Suppl. 10), 2323-2328.
- Radner, G. (2009). *It's always something*. New York, NY: Simon and Schuster.
- Rajan, T. (2002). *Deconstruction and the remainders of phenomenology: Sartre, Derrida, Foucault, Baudrillard*. Stanford, Ca: Stanford University Press.
- Ramfelt, E., Severinsson, E., & Lützen, K. (2002). Attempting to find meaning in illness to achieve emotional coherence: The experiences of patients with colorectal cancer, *Cancer Nursing, 25*(2), 141-149.
- Ramphal, R., Meyer, R., Schacter, B., Rogers, P., & Pinkerton, R. (2011). Active therapy and models of care for adolescents and young adults with cancer, *Cancer, 117*(Suppl. 10), 2316-2322.
- Randall, W., & McKim, A.E. (2008). *Reading our lives: The poetics of growing old*. New York, NY: Oxford University Press.
- Reese, W. (1980). *Dictionary of philosophy and religion: Eastern and Western thought*. Atlantic Highlands, NJ: Humanities Press.
- Richer, M-C., & Ezer, H. (2000). Understanding beliefs and meanings in the experience of cancer: a concept analysis. *Journal of Advanced Nursing, 35*(5), 1108-1115.
- Ricoeur, P. (1970). The conflict of interpretations. In *Freud and philosophy: An essay on Interpretation* (pp. 20-36). (D. Savage, Trans.). New Haven and London, UK: Yale University Press. (Original work published 1965).

- . (1976). Speaking and writing. In *Interpretation theory: Discourse and the surplus of meaning* (pp. 25-44). Fort Worth, TX: Texas Christian University Press.
- . (1984). *Time and narrative* (Vol. 1). (K. McLaughlin & D. Pellauer, Trans.). Chicago, IL: University of Chicago Press. (Original work published 1983).
- . (1985). *Time and narrative* (Vol. 2). (K. McLaughlin & D. Pellauer, Trans.). Chicago, IL: University of Chicago Press. (Original work published 1984).
- . (1986). *From text to action: Essays in hermeneutics II*. (K. Blamey and J. Thompson, Trans.). Evanston, IL: Northwestern University Press.
- . (1988). *Time and narrative* (Vol. 3). (K. McLaughlin & D. Pellauer, Trans.). Chicago, IL: University of Chicago Press. (Original work published 1985).
- Riessman, C. (2008). *Narrative methods for the human sciences*. Los Angeles, CA: Sage.
- Riley, B., Manske, S., & Cameron, R. (2011). Youth excel: Towards a pan-Canadian platform linking evidence and action for prevention, *Cancer, 117*(Suppl. 10), 2281-2288.
- Rimmon-Kenan, S. (2002). The story of 'I': illness and narrative identity, *Narrative, 10*(1), 9-27.
- . (2005). "In two voices, or: Whose life/death/story is it, anyway?" In J. Phelan & P. Rabinowitz (Eds.), *A companion to narrative theory* (pp. 399-412). Oxford, UK: Blackwell.
- Roberge, J. (2011). What is critical hermeneutics? *Thesis Eleven, 106*(5), 5-22.
- Roberts, C., Piper, L., Denny, J., & Cuddeback, G. (1997). A support group intervention to facilitate young adults' adjustment to cancer, *Health and Social Work, 22*(2), 133-141.
- Roberts, C., Severinsen, C., Carraway, C., Clark, D., Freeman, M., & Daniel, P. (1997). Life changes and problems experienced by young adults with cancer, *Journal of Psychosocial Oncology, 15*(1), 15-25.

- Rogoff, B., (2003). *The cultural nature of human development*. New York, NY: Oxford University Press.
- Rothe, J. (2000). *Undertaking qualitative research: Concepts and cases in injury, health and social life*. Edmonton, Canada: University of Alberta Press.
- Rosen, L., Carrier, L.M., & Cheever, N. (2010). *Rewired: Understanding the iGeneration and the way they learn*. New York, NY: Palgrave Macmillan.
- Rosenthal, K. (2009). *Everything changes: The insider's guide to cancer in your 20s and 30s*. Hoboken, NJ: John Wiley & Sons.
- Rowland, J. (1990). Chapter 3: Developmental stage and adaptation: Adult model. In J. Holland & J. Rowland (Eds.), *Handbook of psychooncology: Psychological care of the patient with cancer* (pp. 25-43). New York, NY: Oxford University Press.
- Salliant, F. (1990). Discourse, knowledge and experience of cancer: A life story. *Culture, Medicine, and Psychiatry*, 14, 81–104.
- Sand, L., & Strang, P. (2006). Existential loneliness in a palliative home care setting, *Journal of Palliative Medicine*, 9(6), 1376-1387.
- Sarbin, T. (Ed.). (1986). *Narrative psychology: The storied nature of human conduct*. New York and Westport, NY: Praeger.
- Sartre, J-P. (1968). *Search for a method*. (H. Barnes, Trans.). New York, NY: Vintage Books. (Original work published 1960).
- . (1988). *“What is literature?” and other essays*. Cambridge, UK: Harvard University Press.
- Savage, S., Collins-Mayo, S., Mayo, B., & Cray, G. (2006). *Making sense of Generation Y: The world view of 15-25-year-olds*. London, UK: Church House.
- Scarry, E. (1985). *The body in pain: The making and unmaking of the world*. New York, NY: Oxford University Press.

- Scheper-Hughes, N., & Lock, M. (1987). The mindful body: a prolegomenon to future work in medical anthropology, *Medical Anthropology Quarterly*, 1(1), 6-41.
- Seale, C. (2002). Cancer heroics: A study of news reports with particular reference to gender, *Sociology*, 36, 107-126.
- Shweder, R. (1991). *Thinking through cultures: Expeditions in cultural psychology*. Cambridge, UK: Harvard University Press.
- Shweder, R., Much, N., Mahapatra, M., & Park, L. (1997). The “Big Three” of morality (autonomy, community, divinity) and the “Big Three” explanations of suffering. In A.M. Brandt & P. Rozin (Eds.), *Morality and health* (pp. 119-169). New York, NY: Routledge.
- Sinding, C., & Gray, R. (2005). Active aging—spunky survivorship? Discourses and experiences of the years beyond breast cancer, *Journal of Aging Studies*, 19, 147-161.
- Sinding, C., & Wiernikowski, J. (2008). Disruption foreclosed: older women’s cancer narratives, *Health*, 12, 389-411.
- Smith, B., & Sparkes, A. (2011). Exploring multiple responses to a chaos narrative, *Health*, 15(1), 38-53.
- Smith, S. (1993). *Subjectivity, identity, and the body: Women’s autobiographical practices in the twentieth century*. Bloomington and Indianapolis, IN: Indiana University Press.
- Smith, S., & Watson, J. (2010). *Reading autobiography: A guide for interpreting life narratives* (2nd edition). Minneapolis, MN: University of Minnesota Press. (Original work published 2001).
- Snobohm, C., Friedrichsen, M., & Heiwe, S. (2010). Experiencing one’s body after a diagnosis of cancer, *Psycho-Oncology*, 19, 863-869.
- Sontag, S. (1978). *Illness as metaphor*. New York, NY: Vintage Books.

- Sormanti, M. (2010). Facilitating women's development through the illness of cancer: Depression, self-silencing, and self-care, In D. Jack & A. Ali (Eds.), *Silencing the self across cultures* (pp. 363-381). New York, NY: Oxford University Press.
- Stacey, J. (1997). *Teratologies: A cultural study of cancer*. London, UK: Routledge.
- Statistics Canada. (2009). *Leading causes of death in Canada*. Retrieved from the Statistics Canada website on July 29, 2013: <http://www.statcan.gc.ca/pub/84-215-x/84-215-x2012001-eng.htm>
- Stefaniuk, O. (2009). *A rose grows: Fighting cancer, finding me*. Regina, Canada: Your Nickel's Worth.
- Strawson, G. (2004). Against narrativity, *Ratio XVII*(17), 428-452.
- Struber, M., & Kazak, A. (1999). Chapter 8: The developmental impact of cancer diagnosis and treatment for adolescents. In M. Sugar (Ed.), *Trauma and adolescence* (pp. 143-162). Madison, CT: International Universities Press.
- Sun, S., Schiller, J., & Gazdar, A. (2007). Lung cancer in never smokers: A different disease, *Nature Reviews Cancer*, 7, 778-790.
- Sutcliffe, S. (2011). A review of Canadian health care and cancer care systems, *Cancer*, 117(Suppl. 10), 2241-2244.
- Svenaesus, F. (2000). The body uncanny: Further steps toward a phenomenology of illness, *Medicine, Health Care and Philosophy* 3, 125-137.
- . (2009). The phenomenology of falling ill: An explication, critique and improvement of Sartre's theory of embodiment and alienation, *Human Studies*, 32, 53-66.
- Tang, V., Lee, A., Chan, C., Leung, P., Sham, J., Ho, J., & Cheng, J. (2007). Disorientation and reconstruction, *Journal of Psychosocial Oncology*, 25(2), 77-102.

- Teucher, U. (2001a). Writing the unspeakable: Metaphor in cancer narratives. *Dissertation Abstracts International* Section A: Humanities and Social Sciences. 62:1-A. Jul 2001.
- Teucher, U. (2001b). Writing in the face of death: Norbert Elias and autobiographies of cancer. In T. Salumets (Ed.), *Norbert Elias and human interdependencies* (pp. 159-174). Montreal, Canada: McGill-Queens University Press.
- Teucher, U. (2003). The therapeutic psychopoetics of cancer metaphors: Challenges in interdisciplinarity, *History of Intellectual Culture*, 3(1), 1-15.
- Thomas-Maclean, R. (2004). Understanding breast cancer stories via Frank's narrative types, *Social Science and Medicine*, 58, 1647-1657.
- Thompson, D., Jensen, A., & Bonde, A. (2007). Memories and narratives about breast cancer, *Narrative Inquiry* 17(2), 349-370.
- Thompson, K. (2007). Liminality as a descriptor for the cancer experience, *Illness, Crisis & Loss*, 15(4), 333-351.
- Todorov, T. (1981). *Introduction to poetics*. (R. Howard, Trans.). Minneapolis, MN: University of Minnesota Press. (Original work published 1968).
- Towsley, G., Beck, S., & Watkins, J. (2007). "Learning to live with it": Coping with the transition to cancer survivorship in older adults, *Journal of Aging Studies*, 21, 93-106.
- Tonorezos, E., & Oeffinger, K. (2011). Research challenges in adolescent and young adult cancer survivor research, *Cancer*, 117(Suppl. 10), 2295-2300.
- Turner, V. (1969). *The ritual process: Structure and anti-structure*. Chicago, IL: Aldine.
- . (1981). Social dramas and stories about them. In W.J.T. Mitchell (Ed.), *On narrative* (pp. 137-164). Chicago, IL: University of Chicago Press. (Original work published 1980).

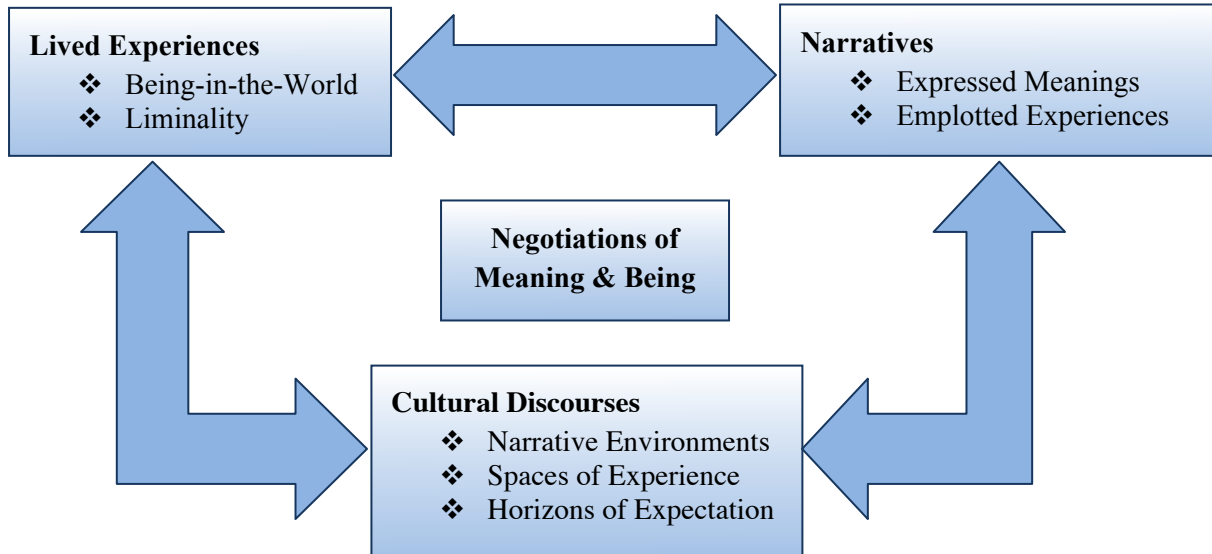
- . (1986). Dewey, Dilthey, and drama: An essay in the anthropology of experience. In V. Turner & E. Bruner (Eds.), *The anthropology of experience* (pp. 33-45). Urbana and Chicago, IL: University of Illinois Press.
- Twenge, J. (2006). *Generation Me: Why today's young Americans are more confident, assertive, entitled—and more miserable than ever before*. New York, NY: Free Press.
- Tymieniecka, A-T. (2001). The complex phenomenon of illness. In A-T. Tymieniecka & E. Agazzi (Eds.), *Life: interpretation and the sense of illness within the human condition: Medicine and philosophy in a dialogue* (pp. xi-xiii). Dordrecht, Netherlands, and Boston, MA: Kluwer Academic.
- Van der Kolk, B., & Van der Hart, O. (1995). The intrusive past: The flexibility of memory and the engraving of trauma. In C. Caruth (Ed.), *Trauma: explorations in memory* (pp. 158-182). Baltimore, MD: John Hopkins University Press.
- Van Gennep, A. (1960). *The rites of passage*. (M.B. Vizedom & G.L. Caffee, Trans.). Chicago, IL: The University of Chicago Press. (Original work published 1909).
- Van Kaam, A. (1966). *Existential foundations of psychology*. Pittsburgh, PA: Duquesne University Press.
- Van Manen, M. (1998). Modalities of body experience in illness and health, *Qualitative Health Research*, 8(1), 7-24.
- Velleman, J.D. (2006). The self as narrator. In *Self to self: Selected essays* (pp. 203-223). Cambridge, UK, and New York, NY: Cambridge University Press.
- Vickberg, S., Duhamel, K., Smith, M., Manne, S., Winkel, G., Papadopoulos, E., & Redd, W. (2001). Global meaning and psychological adjustment among survivors, *Psycho-Oncology*, 10, 29-39.

- Voltaire. (1912). Poem on the Lisbon disaster; Or, an examination of the axiom, "All is well". In *Toleration and other essays* (pp. 255-263). (J. McCabe, Trans.). New York, NY: G.P. Putnam's Sons. (Original work published 1756).
- Wadler, J. (1997). *My breast*. New York, NY: Pocket Books.
- Walboomers, J., Jacobs, M., Manos, M., Bosch, F., Kummer, J., Shah, K., Snijders, P., Peto, J., Meijer, C., & Munoz, N. (1999). Human papillomavirus is a necessary cause of invasive cervix cancer worldwide, *Journal of Pathology*, 189, 12-19.
- Wahrman, D. (2004). *The making of the modern self: Identity and culture in eighteenth-century England*. New Haven and London, UK: Yale University Press.
- Weeks, C. (2011). Jack Layton didn't lose a fight: He died of cancer, *The Globe and Mail*, August 22, 2011.
- White, H. (1981). The value of narrativity in the representation of reality. In W.J.T. Mitchell (Ed.), *On narrative* (pp. 1-23). Chicago, IL: University of Chicago Press.
- Whitehead, L. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis, *Social Science and Medicine*, 62(9), 2236-2245.
- Whyte, S. (1995). Epilogue: Disability between discourse and experience. In B. Ingstad & S. Whyte (Eds.), *Disability and culture* (pp. 267-292). Berkeley and Los Angeles, CA: University of California Press.
- Williams, B. (2004). Dying young, dying poor: A sociological examination of existential suffering among low-socioeconomic status patients, *Journal of Palliative Medicine*, 7(1), 27-37.
- Woodgate, R. (2005). A different way of being: Adolescents' experiences with cancer, *Cancer Nursing*, 28(1), 8-15.

- Woolf, V. (1985). A sketch of the past. In *Moments of being*. London, UK: Hogarth Press.
(Original work published 1938).
- . (2002). *On being ill*. Ashfield, MA: Paris Press. (Original work published 1926).
- . (2012). *The waves*. London, UK: Urban Romantics. (Original work published 1931).
- Yalom, I. (1980). *Existential psychotherapy*. New York, NY: Basic Books.
- . (2008). *Staring at the sun: Overcoming the terror of death*. San Francisco: Jossey-Bass.
- Young-Eisendrath, P. (2009). *The self-esteem trap*. New York, NY: Little, Brown and Company.
- Zammett, E. (2005). *My (so-called) normal life: How I learned to balance love, work, family, friends...and cancer at 23*. New York, NY: Overlook Duckworth.
- Zebrack, B. (2008). Information and service needs for young adult cancer patients, *Support Cancer Care*, 16, 1353-1360.
- . (2011). Psychological, social, and behavioural issues for young adults with cancer, *Cancer*, 117(Suppl. 10), 2289-2294.
- Zickuhr, K., Rainie, L., Purcell, K., Madden, M., & Brenner, J. (2012). *Younger Americans' reading and library habits*. Retrieved from the Pew Internet and American Life Project website on July 4, 2013: <http://libraries.pewinternet.org/2012/10/23/younger-americans-reading-and-library-habits/>
- Zigon, J. (2008). *Morality: An anthropological perspective*. Oxford, UK: Berg.

Appendix A: Theoretical Concepts

Figure A1: Diagrammatic Overview of Theoretical Concepts



Appendix B: Certificate of Ethical Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Ulrich Teucher

DEPARTMENT
Psychology

BEH#
10-180

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
University of Saskatchewan

SUB-INVESTIGATOR(S)
Roberta Woodgate

STUDENT RESEARCHERS
Devon Andersen, Chad Hammond

SPONSOR
SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA (SSHRC)

TITLE
Cancer and Young Adulthood: Making Sense of Life with Illness

ORIGINAL REVIEW DATE
09-Jul-2010

APPROVAL ON
28-Jul-2010

APPROVAL OF:
Ethics Application
Consent Protocol

EXPIRY DATE
28-Jul-2011

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8

Appendix C: Recruitment Pamphlet

Additional Information

Your participation will help us to learn about the specific challenges facing young adults with cancer so that health care may be improved. There is no cost for you to participate in this research except your time.

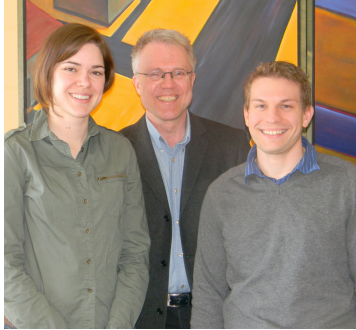
Your participation is entirely voluntary. All information will be kept fully confidential. This research project has been approved by the Ethics Board at the University of Saskatchewan.

Thank you very much for thinking about helping in this research project!



How to Contact Us:

Please feel free to contact Dr. Teucher, Devon Andersen, or Chad Hammond at any time.



Telephone:

(306) 966-2529

E-mails:

Ulrich.Teucher@usask.ca
Devon.Andersen@usask.ca
Chad.Hammond@usask.ca



**Cancer and
Young Adulthood
Making Sense of Life
with Illness**

We Need Your Help!

SSHRC
Social Sciences & Humanities
Research Council

**Invitation to Participate
in a Research Project**

We would like to talk to you about your experiences with cancer. We believe this will help others to understand the specific challenges of life with cancer in young adult-hood. As part of this project, we may ask you to write a short story or journal entry of your experience.

The Lead Researcher

Dr. Ulrich Teucher,
Department of Psychology,
University of Saskatchewan
Phone: 966-2529 (office)
ulrich.teucher@usask.ca

The Research Team

Devon Andersen
Chad Hammond
(Both are PhD students at the
University of Saskatchewan)

Meeting With You

If you are between age 18 and 45, have or have had cancer, and are not currently in the middle of a cancer treatment cycle, please phone or e-mail us. We will gladly answer any questions you may have or provide you with additional information. Upon request, we will send you a full invitation and description of the research project.

With your consent to be part of our study, we will invite you to participate in an individual person-to-person interview. This 90 minute meeting will be held in downtown Saskatoon at the comfortable “Community Village” on 25th Street. We will provide transportation and refreshments.

You will also be given a gift as a token of our sincere appreciation for your time and involvement.

If you wish to participate, please sign the consent form that will come along with the invitation package and mail it to us in our prepaid return envelope. We will then contact you and ask some basic questions such as your age, gender, and ethnic background, and arrange a convenient meeting time with you.

The meetings may be audio-taped so that we can transcribe more accurately what has been said. However, you may request that recording devices be turned off at any time.

Appendix D: Letter of Invitation



Department of Psychology

9 Campus Drive
Saskatoon SK S7N 5A5 Canada
Telephone: (306) 966-6657
Facsimile: (306) 966-6630

Letter of Invitation to Join Research Project

CANCER AND YOUNG ADULTHOOD: MAKING SENSE OF LIFE WITH ILLNESS

We would like to ask for your help so that we can learn more about the specific challenges facing young adults who have or have had cancer. Cancer is a difficult illness to have at any time in life but it seems that one is faced with different challenges depending on the time of life when one is ill. Very little is known how cancer and its treatment affect your life through young adulthood. This research project invites you to share with us some of these challenges, for the purpose of improving the quality of care provided to young adult patients with cancer.

The research project is led by Dr. Ulrich Teucher, Department of Psychology, at the University of Saskatchewan, together with his doctoral students Chad Hammond and Devon Andersen. We are inviting young women and men to participate who have experienced or are experiencing cancer and who fit the following criteria. You:

- are between 18 and 45 years of age;
- are willing to share personal experiences of cancer and cancer treatment in audio recorded interviews and/or in written form.

In particular, we would like to learn how cancer and its treatment

- can affect your personal life, ideas of health and illness, your sense of who you are, and your plans for life as lived through young adulthood,
- can affect your personal goals, beliefs, social supports, family life, and independence, and what these changes, if any, may mean for you.

Short Written Account

If you would like to engage in writing, then we would ask you to send us a short story about your experiences. Writing can provide an opportunity to gather your thoughts and give your experience some form; indeed, some researchers suggest that writing can be helpful in illness. You may want to share whatever you find interesting or important and/or what you think people should know about. In general, we are interested in learning how you think about your illness, its treatment/healing, and its broad impacts on your life. Please write a few pages about your experiences (hand- or typewritten). Please enclose your narrative in the self-addressed, stamped envelope and bring it along to our conversation or please send it to us.

One-on-one Conversation

If you would like to speak with one of us in person then we would ask you to consent to an approximately 90 minute recorded conversation about your experiences with cancer. The conversation could take place at the University of Saskatchewan in the interview room of the Qualitative Research Centre (Arts 285), or at the “Community Village” at 506 25th Street East in downtown Saskatoon, or at another comfortable place. If you live outside of the Province of Saskatchewan, we would be glad to have a recorded conversation with you over the phone.

We would be delighted to have you take part in both activities (written account and conversation) if you so choose. We can provide you with transportation (on request), refreshments, and a gift as a token of our appreciation.

Your confidentiality will be kept strictly: you will be assigned a pseudonym and you will give yourself an identity code (for example, the first three letters of your mother’s maiden name and your age) for the purpose of linking your audio data and/or written materials. All data will be kept in locked storage, and all recordings will be deleted beyond recovery after transcripts have been completed. A final report will be made available upon request.

Sometimes, the topic of cancer may evoke an emotional response. Should this happen, we hope that it will not upset you more than usual. If it does, counselling services at the Saskatchewan Cancer Agency at (306) 585-1831 will be made available to you. While your participation in this research project is hoped to help us learn about the challenges of living with cancer in young adulthood, your participation is in itself not a part of your medical therapy and is not explicitly intended to have therapeutic benefits. Your participation is entirely voluntary. If you have any concerns you need not answer questions that you might feel uncomfortable about, or you may withdraw from the study at any time and/or you may withdraw information at any time (until the final report is written up), without fear of any negative repercussions.

Your choice to participate or not will not be communicated to your physicians or anybody else and will in no way affect your medical care.

It is hoped that this research project will help healthcare professionals and caregivers to better understand the specific challenges facing young adult patients who live with cancer. If you have any questions, please contact Chad Hammond, Devon Andersen, or Dr. Ulrich Teucher by telephone at (306) 966-2996 or email us at illness.stories@gmail.com. If you wish to participate, please sign the enclosed Consent Form, keep one copy for yourself, and mail the other copy to us by using the self-addressed and stamped envelope. We will then make contact with you and set up a meeting time that is convenient for you.

We thank you for your time and look forward to hearing from you!

Sincerely,

Dr. Ulrich Teucher, Associate Professor
Program for Culture and Human Development, Department of Psychology
Co-Director QRC Qualitative Research Centre, College of Arts & Sciences
University of Saskatchewan, 9 Campus Drive, Saskatoon SK S7N 5A5, Canada
Phone (306) 966-2996 Fax (306) 966-6630 Email: illness.stories@gmail.com

Appendix E: Consent Form



Department of Psychology

9 Campus Drive
Saskatoon SK S7N 5A5 Canada
Telephone: (306) 966-6657
Facsimile: (306) 966-6630

Consent Form to Join Research Project

CANCER AND YOUNG ADULTHOOD: MAKING SENSE OF LIFE WITH ILLNESS

You are invited to participate in a research project entitled “Cancer and Young Adulthood: Making Sense of Life with Illness.” Please read this form carefully and ask any questions you might have.

Research Assistant:

Chad Hammond

Research Assistant:

Devon Andersen

Research Leader:

Dr. Ulrich Teucher

Dept. of Psychology, University of Saskatchewan Phone: (306) 966-2996 E-mail: illness.stories@gmail.com

Purpose and Procedure: We are asking for help from young adults between 18 and 45 years of age who have or have had cancer, for the purpose of learning more about the specific challenges facing young adults at this time of your lives. We would be very grateful if you would be willing to share some of your personal experiences in a one-on-one conversation (about 90 min) and/or in written form. We are hoping that what we learn from you will help us better understand the experience of life with cancer so that cancer care for younger patients can be improved for the future.

Short Written Account: If you would like to engage in writing, then we would ask you to send us a short story about your experiences. Writing can provide an opportunity to gather your thoughts and give your experience some form; indeed, some researchers suggest that writing can be helpful in illness. You may want to share whatever you find interesting or important and/or what you think people should know about. In general, we are interested in learning how you think about your illness, its treatment/healing, and its broad impacts on your life. Please write a few pages about your experiences (hand- or typewritten). Please enclose your narrative in the self-addressed, stamped envelope and bring it along to our conversation or please send it to us.

One-on-one Conversation: If you would like to speak with one of us in person then we would ask you to consent to an approximately 90 minute recorded conversation about your experiences with cancer. The conversation could take place at the University of Saskatchewan in the interview room of the Qualitative Research Centre (Arts 285), or at the “Community Village” at 506 25th Street East in downtown Saskatoon, or at another comfortable place. If you live outside of the Province of Saskatchewan, we would be glad to have a recorded conversation with you over the phone.

We would be delighted to have you take part in both activities (written account and conversation) if you so choose. We can provide you with transportation (on request), refreshments, and a gift as a token of our appreciation.

Potential Risks and Benefits: Talking about cancer can sometimes be upsetting. If this happens to you during the interview, or in the case that you might be writing about your experience, and you find yourself becoming unduly upset, please let us know. Please feel free to contact a counsellor at the Saskatchewan Cancer Agency Counselling and Support Services at (306) 585-1831. While your participation will inform us about the challenges of living with cancer in young adulthood, and may help improve cancer care, your participation is in itself not part of your treatment and has no direct benefits as a therapy.

Confidentiality: All the information gathered during this research project will be STRICTLY CONFIDENTIAL. We will use a pseudonym instead of your name and random identity codes to link any data together. Your name, and the fact that you attended the interview and/or wrote about your experience will not be revealed to anyone. The final report will contain general ideas only and we will NOT include your name or any other identifying information. As well, we want to assure you that your participation or non-participation will not affect your standing with your Health Region in any way, even if you tell us you want something changed, or want to withdraw from the study.

Storage of Data: We will NOT be putting your name or any personal identifying information about you anywhere in the write-up of the research. The notes that we make from our discussions, any other data, and a copy of this consent form will be stored separately in locked cabinets in Dr. Teucher’s office in the Department of Psychology at the University of Saskatchewan for at least five years after the completion of the study. After that time, everything will be destroyed beyond recovery.

Right to Withdraw: You may choose not to answer individual questions that you might feel uncomfortable about, and you may withdraw from the study at any time and/or may withdraw information at any time up until the final report is written, without fear of any negative repercussions. Should you decide to withdraw, your services through your Health Region will not be affected. Upon withdrawal, all data including any recordings and/or written materials, will be destroyed beyond recovery and NOT included in the research. You are free to choose how you would like to answer the questions that we will be discussing. If you feel uncomfortable with the recording device, you may request that it be turned off. In the case that you agree to write a short written account of your experiences, and you do send us a personal account of yours, we will view your written text as a sign of your consent to participate in this part of the study.

Questions: If you have any questions or concerns about anything discussed in the interview, or about writing something about your experience, please feel free to ask us at any time during the meeting or at a later date. This research project has been approved on ethical grounds by the University of Saskatchewan

Behavioural Sciences Ethics Board on 28 July 2010. Any questions about your rights as a participant in this research may be addressed to that committee through the Office of Research Services at (306) 966-2084. If you would like to receive a summary of the final report, please contact us at (306) 966-2669.

Identity Code: Our study has two parts (should you also participate in the writing) and we would like to put these parts of your contributions together. Therefore we ask that you make up a personal identity code (for example, the first three letters of your mother's maiden name and your age). In this way your confidentiality will be preserved. See next page:

Your Identity Code:

1. Please fill in your personal identity code [][][]

(first three letters of your mother's maiden name)

2. Your age:

Consent to Participate: I have read and understood the description provided above; I have been provided with a chance to ask questions and my concerns have been answered satisfactorily. I consent to participate in the research project described above and understand that I may withdraw this consent at any time before the final report has been written; upon withdrawal, all information provided by me will be destroyed beyond recovery. A copy of this form has been given to me for my records.

(Signature of Participant) (Date) (Phone number)

(Signature of Researcher) (Date)

Appendix F: Interview Protocol

Questions for C&YA Individual Interview

Date: _____ **Time:** _____

Location: _____

Consent Form Reviewed and Signed: _____

Age: _____

Ethnicity: _____

Pseudonym of Participant(s): _____

Interviewer: _____

Legend for Pseudonym:

- *P Participant #*
- *CYA (Cancer & Young Adulthood)*
- *M/F Male/Female)*
- *AGE (In years)*
- *S (Saskatoon), PA (Prince Albert)*
- *Example: Jack Black aged 28 from Moose Jaw: P1CYAM28MJ*

1. Introductory Considerations

Introduction Morgan (1997)	<ul style="list-style-type: none">• Overview and Context: The interviewer will introduce himself/herself
	<ul style="list-style-type: none">• Welcome & thank participant for volunteering to be part of the study• Explain the consent form.• Inform participant will be assigned a pseudonym

2. General Discussion About Young Adulthood

Challenges of Young Adulthood

- **Please** let me say a few words before we begin. When we ask you to tell us about your experiences, there is no **right or wrong** response.
- Cancer and its treatment can affect different persons in very **different ways**, during different stages of their lives.
- In order to better understand how cancer affects us when we are in young adulthood, it would be good if we could first talk for a moment what the **experience of young adulthood** itself is like, compared to when we were younger or when we might be older
- Life in young adulthood can **affect us in many ways**:
 - our bodies,
 - our ability to think,
 - how we feel,
 - how we relate with or may depend on others,
 - our expectations about the rest of our lives, and
 - the activities we find important in our lives.
- So I would like to ask you to please tell me first what your experience of young adulthood has been like.

Notes _____

Images of Young Adulthood

- Talking about Young Adulthood, would you have an image or metaphor or two, that could illustrate for somebody else what you personally think young Adulthood is like?
- What would you say Young Adulthood is like?

Notes _____

3. Introductory Questions

Type of Cancer & Treatment

- Before we begin to speak about the challenges of cancer when we are in young adulthood I would like you to please describe in your own words
 - What kind of cancer you have or have had
 - what kind of medical treatments you have or have had
 - and what other non-medical treatments you may have used

Notes _____

4. General Discussion About Cancer

Challenges of Cancer

- We have now talked about life in young adulthood.
- I would like to ask you now to please tell me how life with cancer has been affecting you as you are living through young adulthood
- Life with cancer can affect us in many ways; for example, it can affect
 - our bodies
 - our ability to think,
 - how we feel,
 - how we relate with or may depend on others,
 - our expectations about the rest of our lives, and
 - the activities we find important in our lives.
- **How has cancer been affecting you at this stage of your life, being in young adulthood**

Notes _____

5. Supplementary Questions (if not answered in Interview earlier)

5a. Bodily changes	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our bodies as we are in young adulthood now - and how we think about those changes. • Has your experience with cancer affected your body as you are a young adult now and what do you think about these changes?
5b. Thinking	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our ability to think as we are now in young adulthood - and what we might make of those changes. • Has your experience with cancer affected your ability to think as you have entered young adulthood and what do you make of these changes?
5c. Emotions	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our emotions at this time of our lives - and what we might think of those changes. • Has your experience with cancer affected your emotions, being a young adult, and what do you think about these changes?
5d. Relations	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our relations with others, for example, our dependence or independence - and what we might think of those changes. • Has your experience with cancer affected your relations and how you may depend on others as you are now a young adult and if so, what do you think about these changes?
5e. Expectations	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our expectations about our future life as we are young adults. • Has your experience with cancer affected your expectations about the future of your life as you are in young adulthood and what do you think about those changes?
5f. Activities	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our activities as we are young adults. • Has your experience with cancer affected activities you find important or meaningful in your life, and what do you think about those changes?

5g. Life's Limitations	<ul style="list-style-type: none"> • Another aspect that we would like to learn about is how cancer might affect our perceptions of life's limitations as we are young adults. • Has your experience with cancer affected your perception of life's limitations, and what do you think about those changes?
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6. Images

6a. Images of Cancer	<ul style="list-style-type: none"> • Earlier I asked you about images that might illustrate what Young Adulthood is like. • Sometimes it can be difficult to explain to others what the experience of cancer or its treatment are like. We then use images (or metaphors), as a likeness for that which is difficult to explain. • Here is an unrelated example of an image. Say, you want to illustrate what happiness is like. You then might say "Happiness is like . . . a deep well." • Based on your own personal experience, what image or images might help to understand what your experience of cancer is like? • What would <u>you</u> say: Cancer is like ... <p>Prompt 1, if needed:</p> <ul style="list-style-type: none"> • Let me explain this with an example from another illness. • How do we explain, e.g., what the experience of Alzheimers is like? • It turns out that some patients compare it to snow softly falling, or leaves softly falling, to illustrate in a way how the pieces of memory are slowly falling. They might say Alzheimer's is like slowly falling leaves. <ul style="list-style-type: none"> • Based on your own personal experience, what image or images might help to understand what your experience of cancer is like? • What would <u>you</u> say: Cancer is like ... <p>Prompt 2, if needed:</p> <ul style="list-style-type: none"> • There are actually many ways how cancer patients have imagined the experience of cancer. • Interestingly these images can differ widely form each other. They may work for one patient but not another. • E.g., one might say that cancer is, say, somewhat like an enemy. Another might say cancer is more like a teacher or even a friend. • Another, again, might say cancer is like a journey where you have choices, while another feels there is no choice, rather, cancer is like, say, rolling the dice.
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	<ul style="list-style-type: none"> • As you see, these examples are all very different, and there are many other examples possible. • Based on your own personal experience, what image or images might help to understand what your experience of cancer is like? • What would you say: Cancer is like . . .
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Cancer is like . . . _____

6b. Cancer Treatment Images	<ul style="list-style-type: none"> • In a similar way, based on your own personal experience, what image or images might help to understand what your experience of cancer treatment is or was like? • What would you say: Cancer Treatment is like . . .
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Cancer Treatment is like . . . _____

6c. Comforting Images	<ul style="list-style-type: none"> • Aside from images for cancer or its treatment, we might also have other images that might help us find some general comfort or support or help us find some resolution in a time of illness and treatment. • What image would you say provides you with comfort or support in a time of illness and treatment?
--------------------------------------	---

Comforting Image: _____

7. Other Questions

7a. Time	<ul style="list-style-type: none">• Another aspect that we would like to learn about is the matter of time• Different people can have different ideas about time in their lives, particularly if they have cancer when they are young.• Has your sense of the passage of time changed as you have become a young adult? How has the experience of cancer further influenced that experience?• Has this perhaps changed sense of time had an influence on your expectations about life?
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Notes _____

7b. Sense of Identity	<ul style="list-style-type: none">• Has cancer affected your sense of identity, or who you are as a person? How so?
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Notes _____

7c. Lead Life	<ul style="list-style-type: none">• Has cancer affected how you feel about or lead your life? How so?
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Notes _____

7d. Control	<ul style="list-style-type: none">• Has cancer affected your sense of control over your life? How so?
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Notes _____

7e. Doctors, Nurses	<ul style="list-style-type: none"> • How were you treated by your doctors and nurses?.
Notes _____ _____ _____ _____	

7f. After Life	<ul style="list-style-type: none"> • Some people believe in the hope that something in us might live on in some way after this life, perhaps in the work we have accomplished, or through the family we may have raised, or in the form of a soul. • Do you share such ideas in some way? • If so, have such ideas been useful as you have been dealing with illness and growing older?
Notes _____ _____ _____ _____	

8. Closing

Closing Question	<ul style="list-style-type: none"> • Is there anything you want to add to this discussion that you feel is important for us to know?
Notes _____ _____ _____ _____	

Closing Remarks

Reminder for those who wish to write and do so after the interview that there will be information how to do so
 Presentation of gift, and thanks for participation in session

Appendix G: Sample Characteristics

Figure G1: Summary of Participants' Demographics

Demographic	N				
Residence		Age in Years		Gender	
British Columbia	1	≤ 20	1	Female	13
Alberta	3	21-24	2	Male	8
Saskatchewan	6	25-29	5		
Manitoba	2	30-34	6		
Ontario	8	35-39	4		
Nova Scotia	1	≥ 40	3		

Figure G2: Summary of Participants' Cancers

Illness Information	N				
Cancer Type		Cancer Stage		Time since Diagnosis	
ALL	3	Stage 0	1	0-2 years	11
Brain	3	Stage 1	3	3-5 years	5
Breast	2	Stage 2	2	6-10 years	1
Cervical	2	Stage 3	4	> 10 years	4
Colorectal	2	Stage 4	2		
Hodgkin's	4	Unknown	9		
Lung	1				
Non-Hodgkin's	1				
Testicular	2				
Urachal	1				

Appendix H: Narrative Genres

Figures H1: Narrative Genres within Theoretical Framework

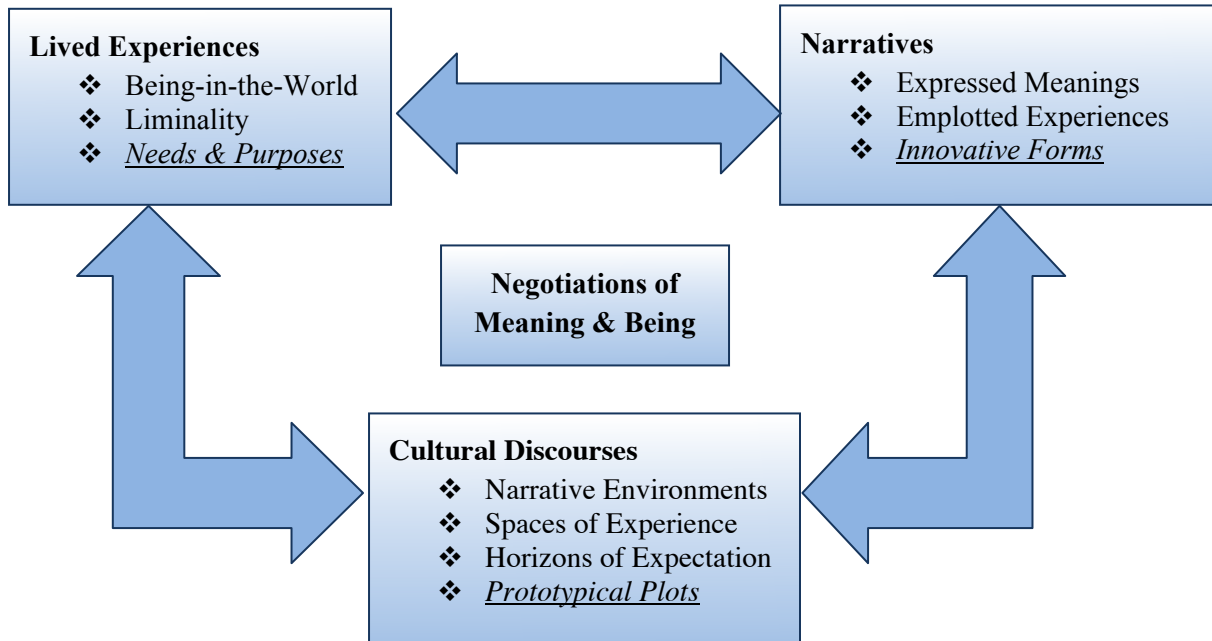


Figure H2: Different Moments of Meaning



Figure H3: The Hierarchical Dominance of Moments of Meaning



Appendix I: Narrative Identities

Figure II: Narrative Identity within Theoretical Framework

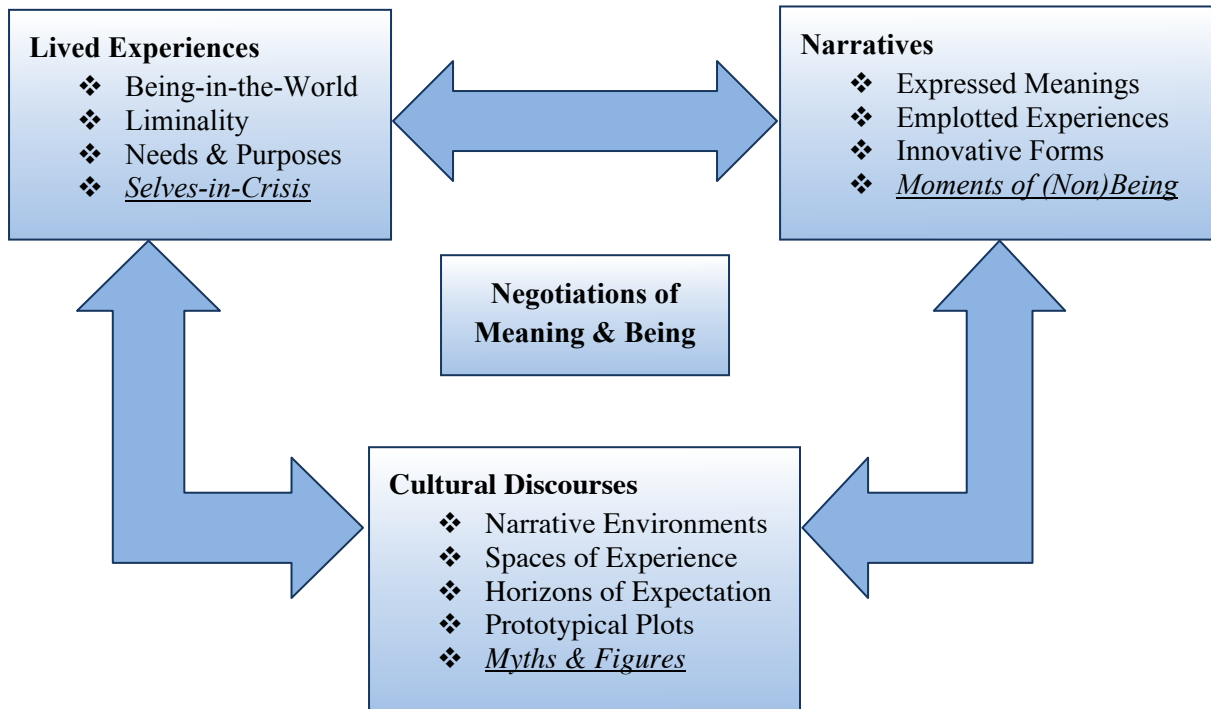


Figure I2: Narrative Sequences of Liminality

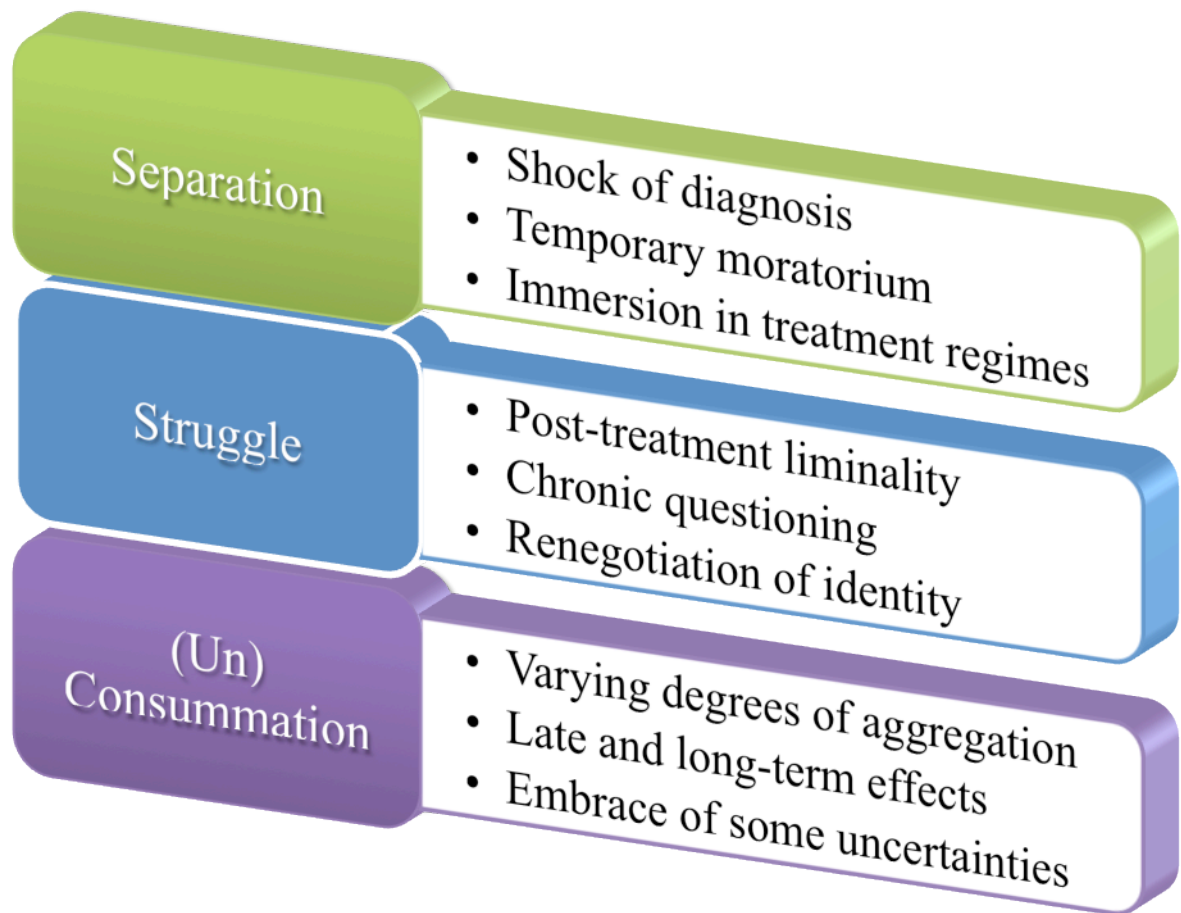


Figure I3: Mythic Figures from Prototypical Plots

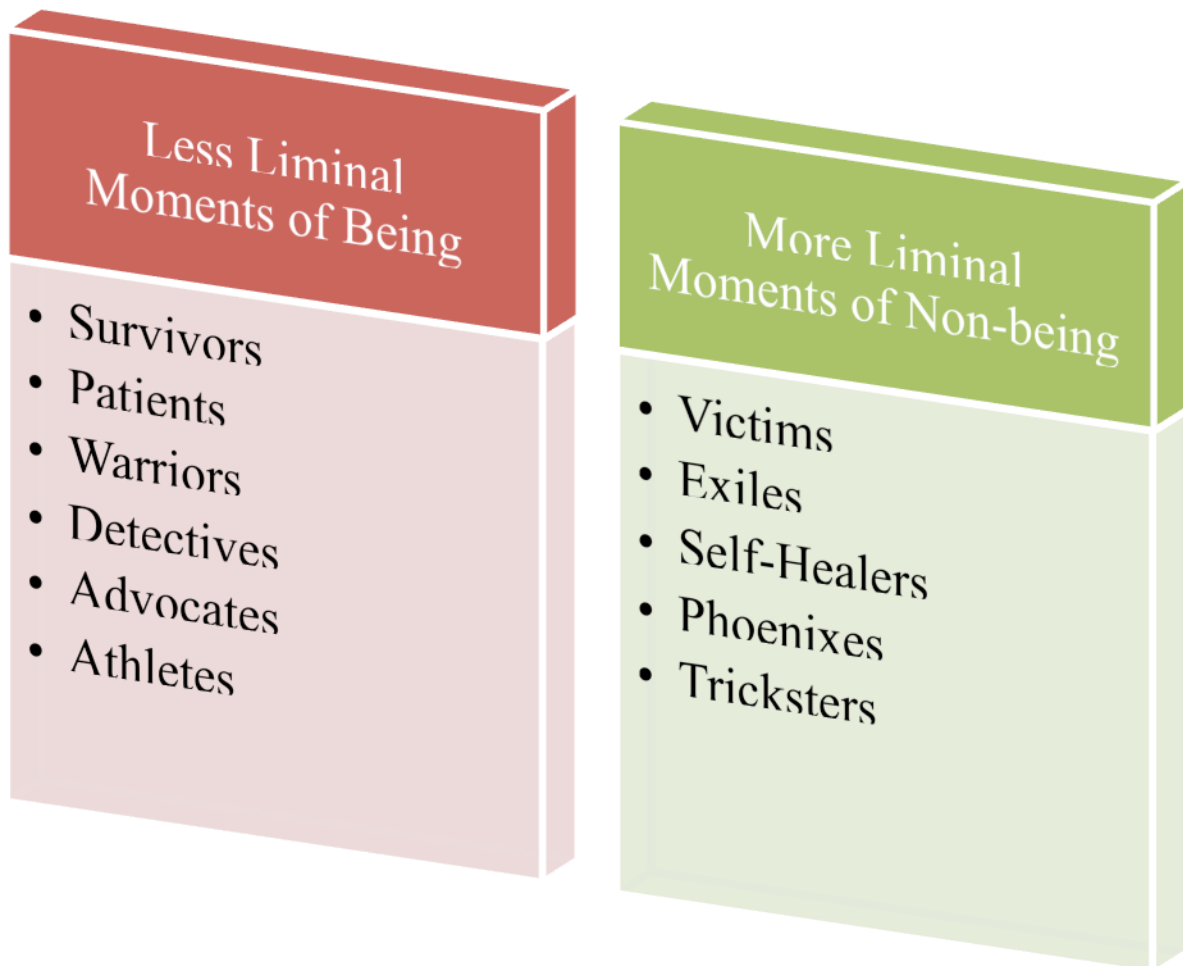


Figure I4: Intersubjectivities shaping Being and Meaning

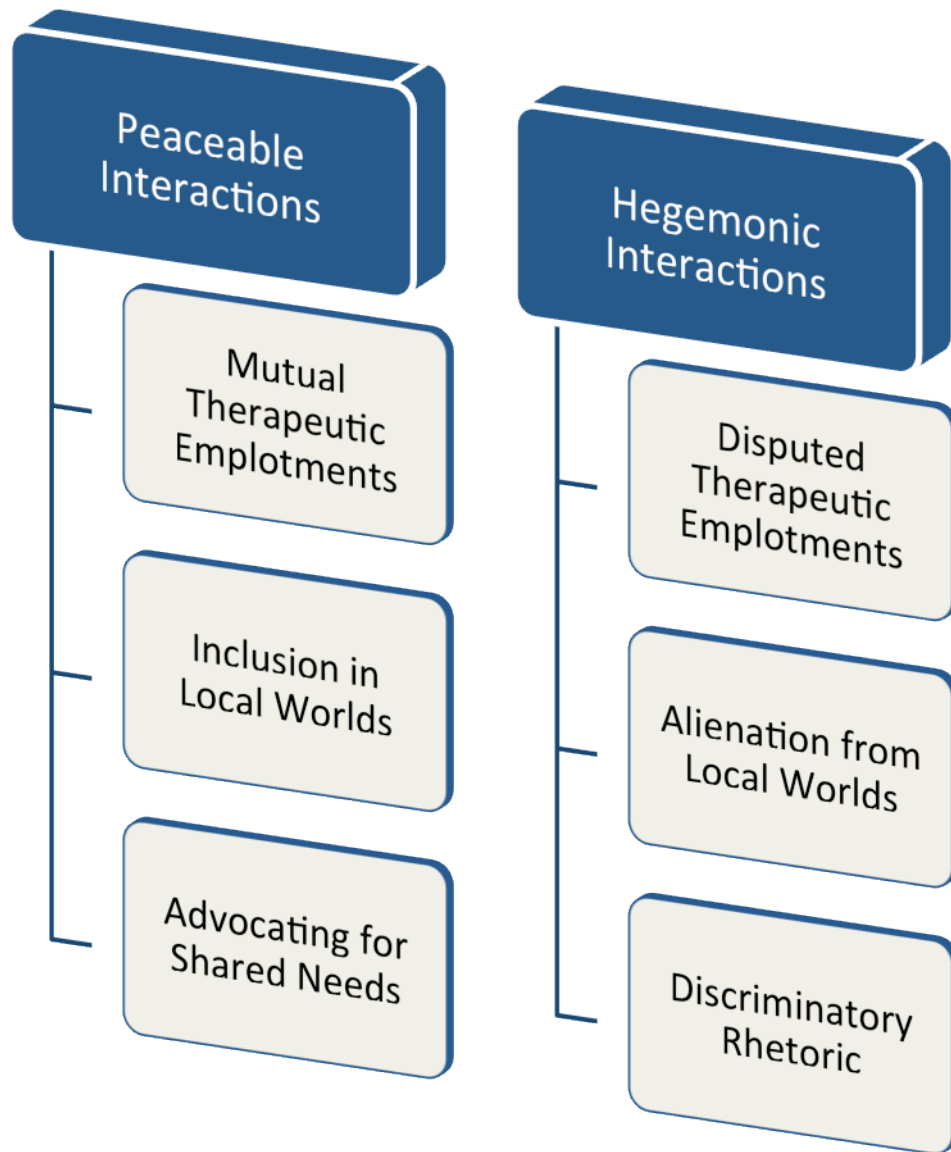


Figure I5: Developmental Identities before Cancer

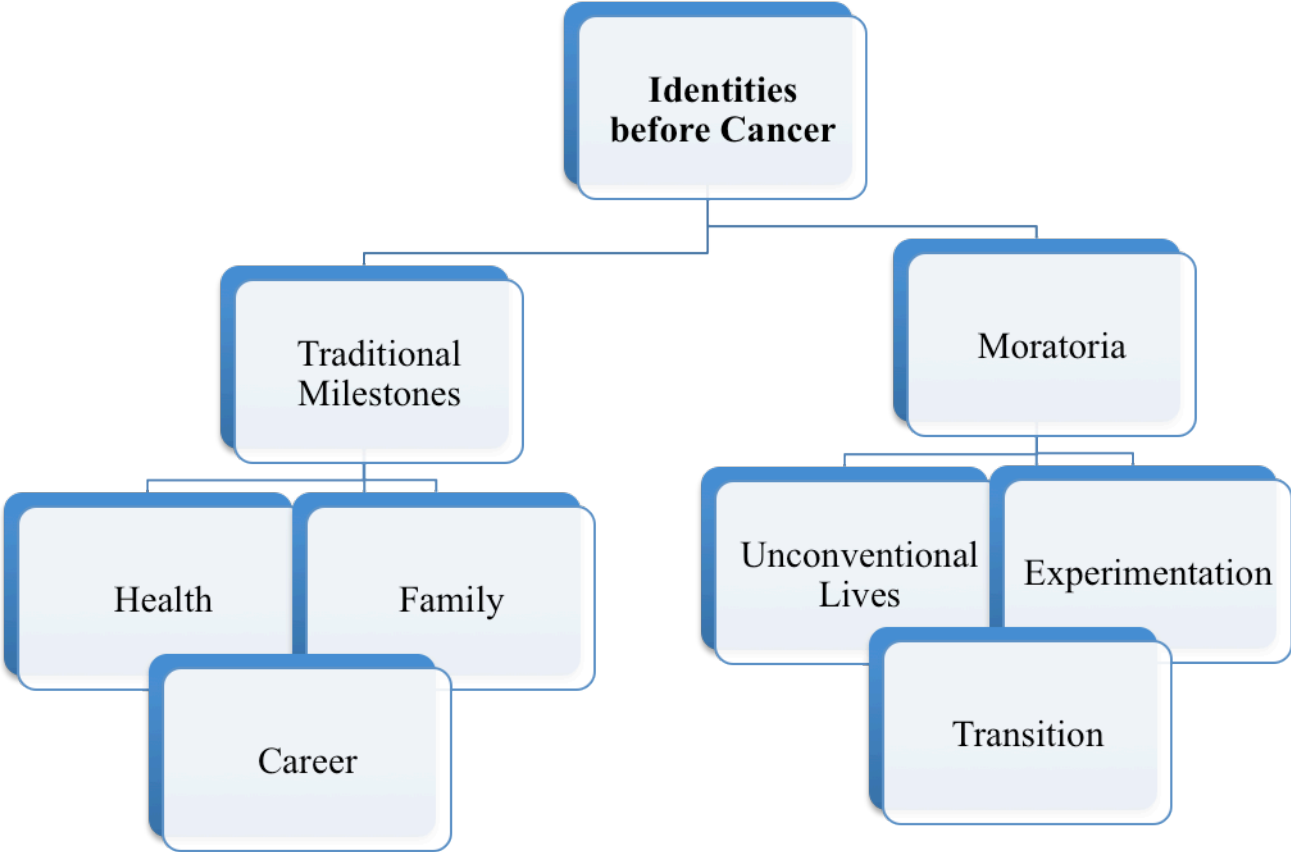


Figure I6: Separations from Identities because of Cancer

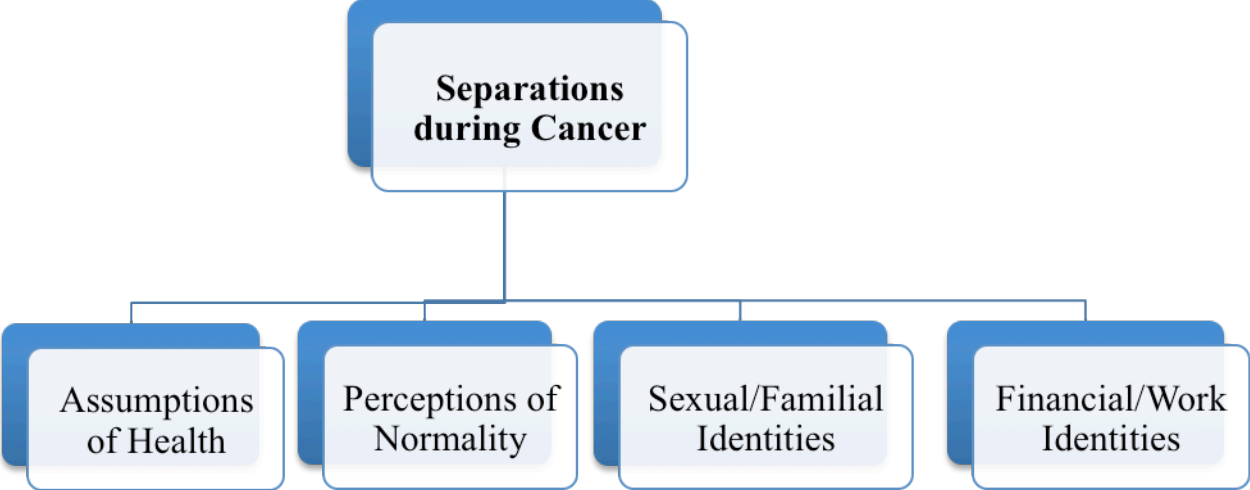


Figure I7: Struggles with Identities during and after Treatment

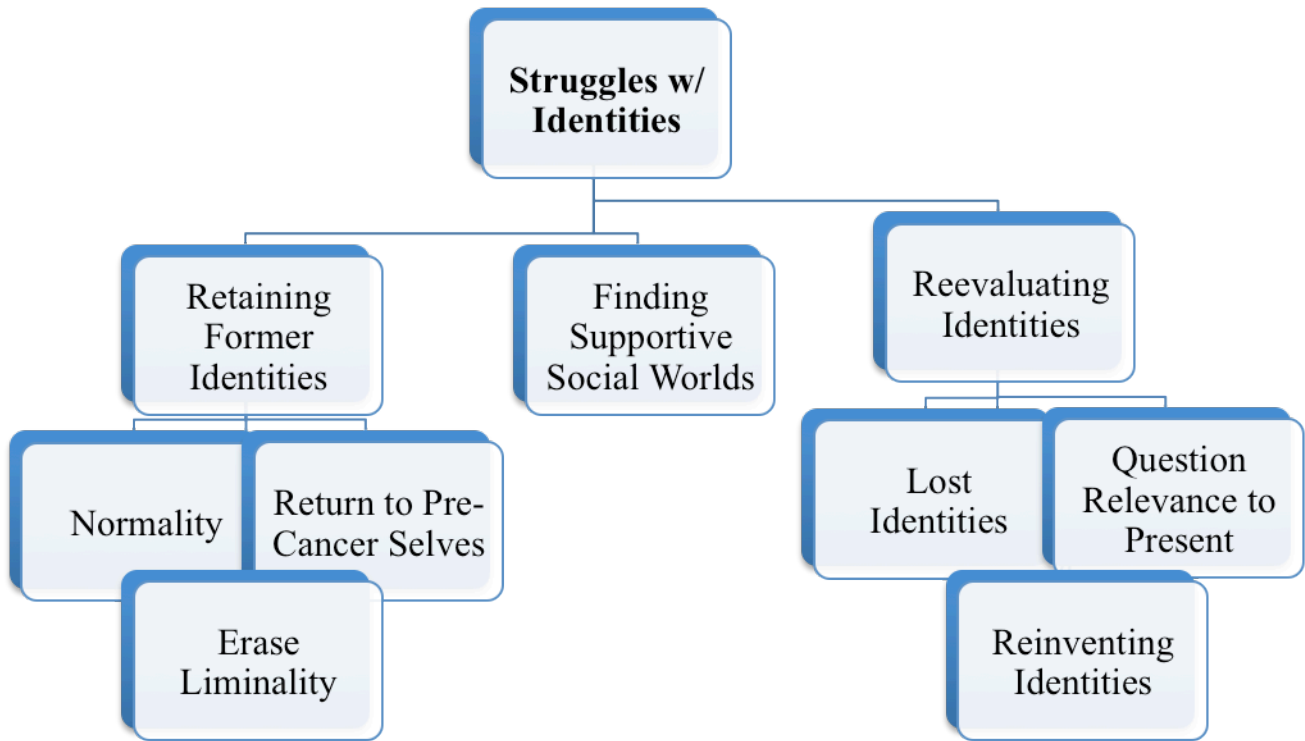
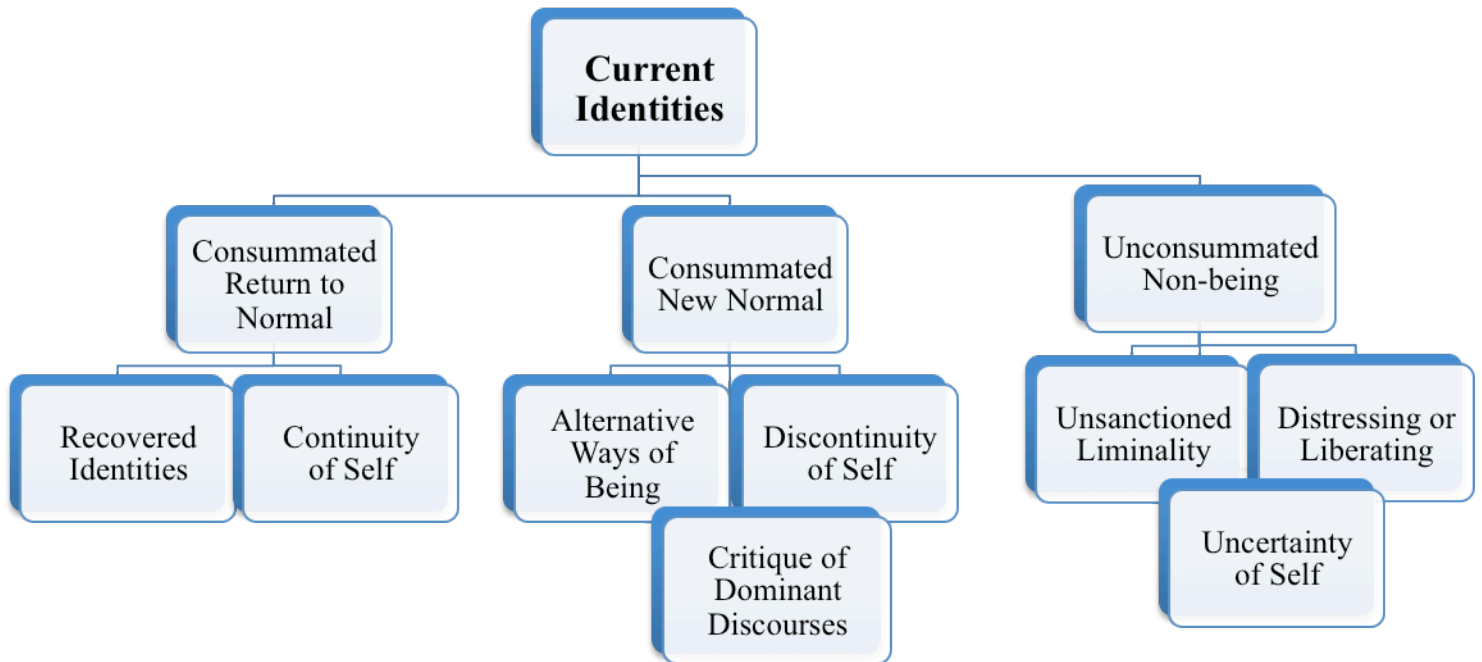


Figure I8: (Un)Consummated Identities in the Present



Appendix J: Moral Quests

Figure J1: Moral Quests within Theoretical Framework

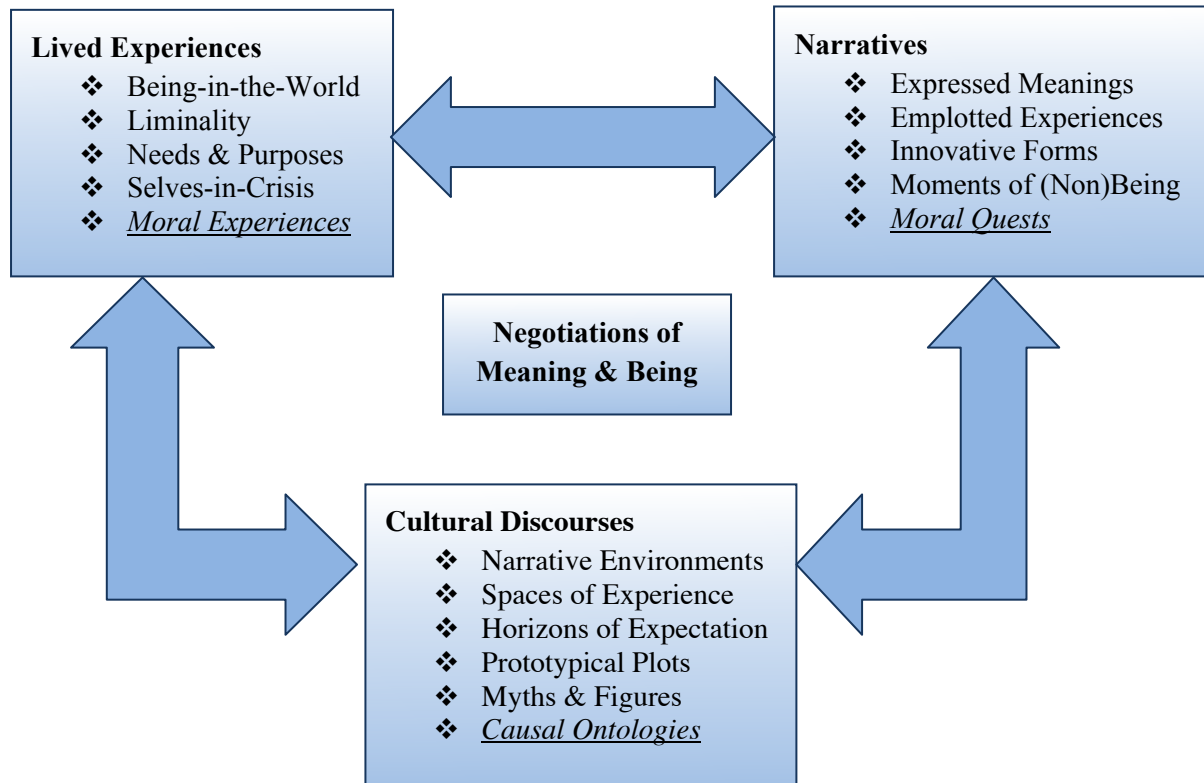


Figure J2: The Hierarchical Dominant of Causal Ontologies

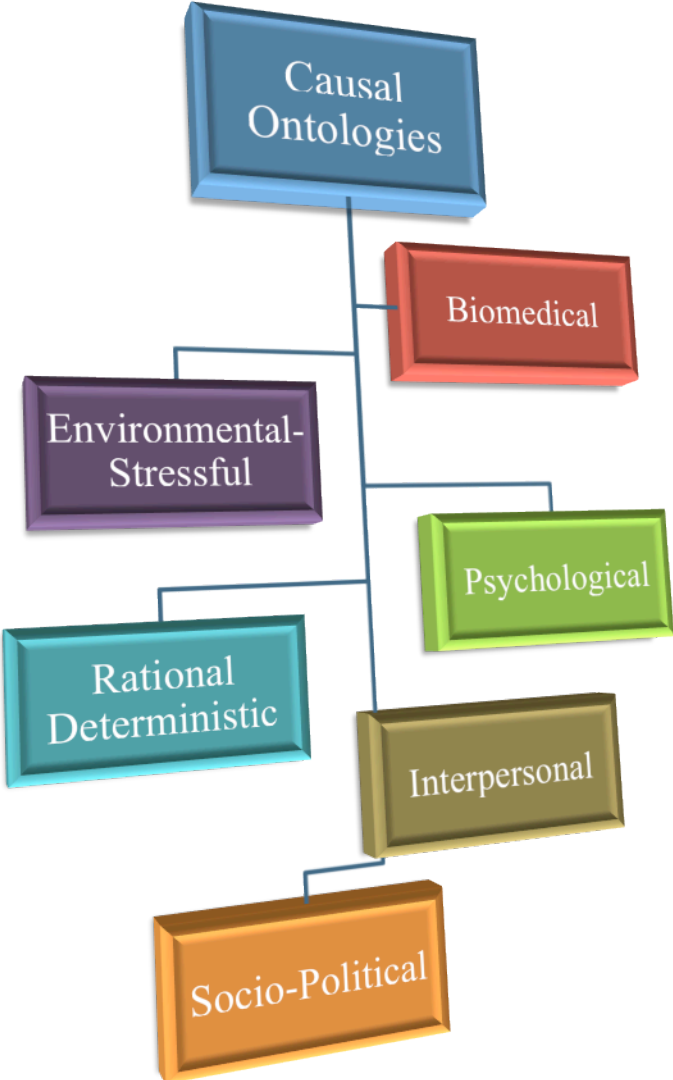


Figure J3: Moments of Existential Questioning

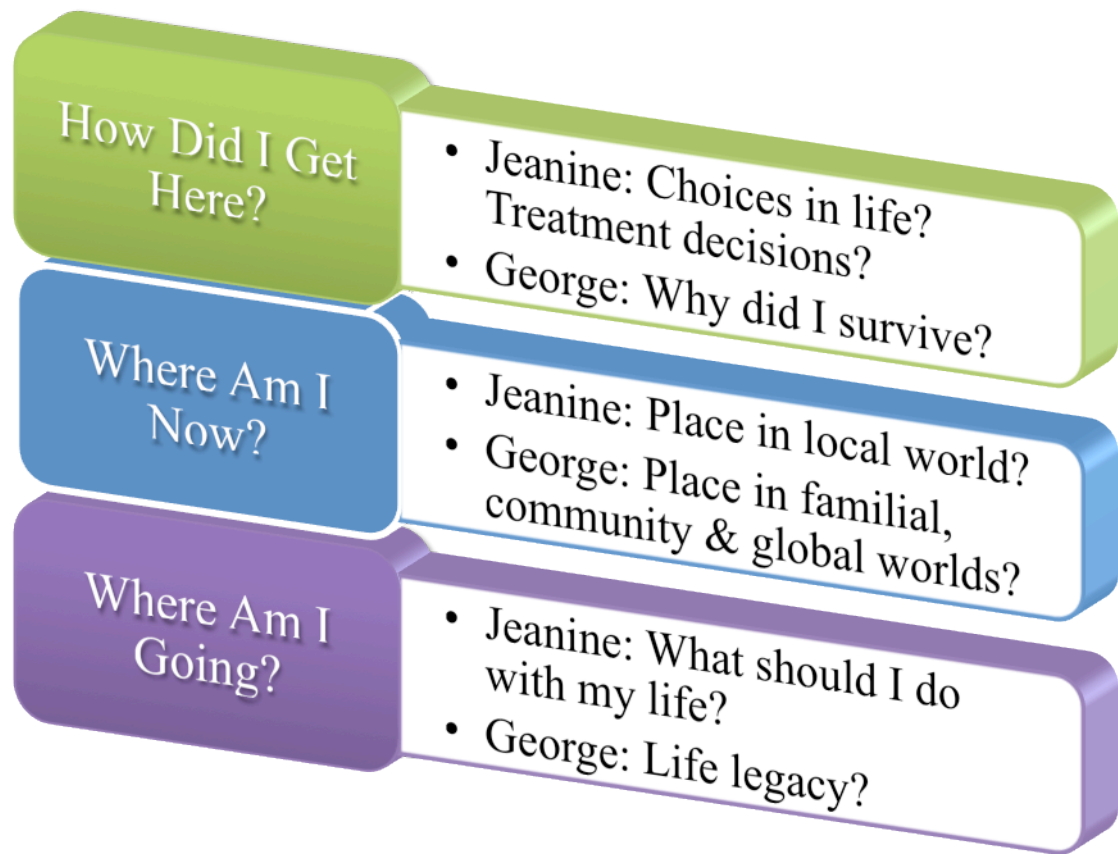


Figure J4: Moments of Moral Explorations

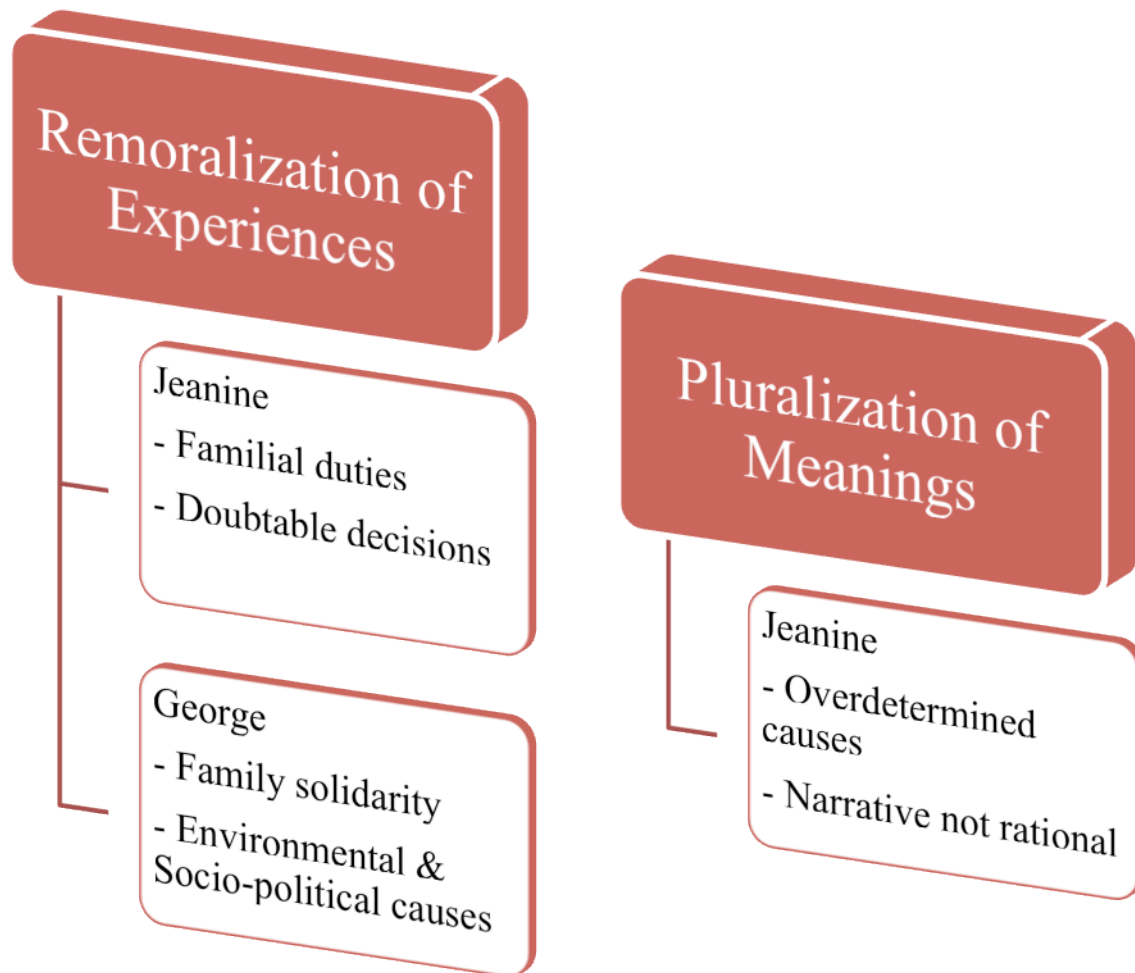


Figure J5: Moments of Moral Living

