

Untold Stories, Unheard Lives:
A Study of How Adolescents with Cancer Create Selfhood through Narrative

by
Trisha Paul

A thesis presented for the B. S. degree
with Honors in
The Department of English
University of Michigan
Winter 2014

For youth with cancer

Acknowledgements

I'd like to start by thanking everyone who has listened to me talk about my research. An immeasurable number of people have supported me and helped shape my ideas, and each perspective has been invaluable to me in conceptualizing and carrying out this project.

First of all, I'm thankful to have been able to pursue my passion for English and my fascination in medicine. My high school English teacher, Mr. Eldon, encouraged my curiosity and showed me how fulfilling the study of literature can be. Donovan and Jenni spent countless Fridays with me at Mott, sharing their experiences so I could better understand childhood cancer.

To those who responded to the email of a stranger: Dr. B, whose steadfast faith in my ambitions has exemplified true mentorship over the years. Professor Alexandra Minna Stern introduced me to illness narratives, enabling me to connect the dots of literature and medicine.

Jennifer Wenzel and my thesis cohort motivated me through every step of the process. Professor Wenzel, your dedication to our work and thorough feedback has been invaluable. Thanks to my fellow thesis writers, namely Eli Fenyes: it's been a pleasure to work with you all. I'm also indebted to my close friend Nivine Elhor, for willingly dedicating her own time to help.

I am sincerely grateful for my thesis advisor, Melanie Yergeau. Melanie, I can't thank you enough for listening patiently to my wild ideas and stream of consciousness, always pushing the boundaries of how I think. Your keen perception and passion for rhetoric never cease to amaze me; with your guidance, I believe that I've found a voice in my writing and my place in the field of English. You've inspired me more than you know; I admire you beyond articulation.

Special thanks also to pediatric oncologist Dr. Rajen Mody for believing in my goals. Without him, this project would never have been viable. He emboldened me to expand this research more than I had ever imagined, and I hope to have his energy as I delve into medicine.

I appreciate the financial and overall support that made this research possible from the Department of English, LSA Honors Program, and Division of Pediatrics Hematology/Oncology.

To all those at C.S. Mott Children's Hospital. Thanks to the entire Peds Heme/Onc staff, especially J.J. Bouchard, for welcoming me warmly, assisting me whenever possible, and enthusiastically asking about how my project was going. My heartfelt gratitude goes out to Mott families, whose encouragement of my research and aspirations has always meant so much to me.

Most importantly, I am grateful to the children and adolescents at Mott. It has truly been an honor to spend time getting to know these youth with cancer over the years. Thank you for sharing part of your life with me. You have touched my own life, and for that, I thank you.

Oh, thanks to two of my best friends: my parents. Thanks mom and dad, for everything.

Abstract

Illness narratives, especially those about cancer, have become increasingly prevalent in recent years in an attempt to communicate experiences with illness. Yet amongst cancer narratives, experiences of childhood and adolescent cancer have largely been left untold. Stories shared about youth with cancer have mostly been written from other perspectives such as by parents, health professionals, or public relations personnel, but rarely from an adolescent's own view. While some memoirs confront cancer retroactively, such as Lucy Grealy's *Autobiography of a Face*, few or none are written by adolescents as they are currently experiencing cancer.

This thesis aims to fill the void of narratives by adolescents with cancer. Since cancer is a living reality for so many adolescents, it is troublesome that these youth have not had the opportunity to give voice to these experiences. It is problematic, I argue, not to listen to these often unspoken voices, for they can provide insight into marginal experiences as told by the ill. These narratives can reveal the subjective illness experiences of a diverse population.

My thesis explores how adolescents with cancer at the University of Michigan C.S. Mott Children's Hospital express their experiences through writing, drawing, and speaking about cancer. I sat down with adolescent patients and asked guiding questions that they responded to through any or all of these mediums. These narratives illuminate how adolescents make sense of their cancer and treatment as well as how these understandings affect their developing sense of self.

My introduction begins by tracing the history of illness narratives and autobiographies about childhood to understand the current void, and thereby the urgency, of life writing by adolescents with cancer. In the first chapter, I delve into my research methods and the ethical concerns that arise with adolescent involvement and researcher intervention. I acknowledge how my methodological approach has in effect influenced the creation of these narratives.

Chapter two explores how adolescents define cancer and chemotherapy. While many defined cancer as a disease, elaborations often deviated to include but also challenge perceptions of cancer as an uncontrollable excess, an impairment or disability, and an evil. Many perceived chemotherapy similarly and sometimes struggled to distinguish between the two. I navigate through these blurred understandings, ultimately to recognize their implications on adolescents with cancer.

Building off these perspectives, the third chapter investigates how experiences of cancer and chemotherapy affect an adolescent's sense of self. Narrative exposes conceptualizations of the self, specifically pertaining to the period of adolescence, the body with cancer, the self as a patient, the desire for normalcy, and the self as a social being.

In the fourth and final chapter, I expand the implications of my interactive research methodology and of these adolescent cancer narratives. I consider the broader impact my research may have on narrative studies, medicine, and the interdisciplinary fields of medical humanities and narrative medicine. Most importantly, this thesis enables adolescent agency and allows these individuals, with personal and intimate experiences of their own, to enter into the discourse that surrounds their lives.

CONTENTS

Introduction.....	1
Chapter One: Methods and Ethics: Eliciting Adolescent Cancer Narratives	17
Adolescent Involvement	21
Participation	21
Settings.....	23
Purpose.....	25
Researcher Intervention	27
Questions.....	27
Risks.....	28
Analysis.....	30
Chapter Two: “Bad Blood Cells, Good Treatment”: Conceptualizing Cancer and Treatment	33
“Can’t really control it”: Cancer and chemotherapy as uncontrollable	35
“Disadvantage”: Cancer and chemotherapy as impairments and disabilities	38
“It’s scary and it’s awesome”: The evil and the good of cancer and chemotherapy	40
Chapter Three: “Cancer at a Crappy Age”: Creating an Adolescent Self with Cancer	49
“I am, like, having to grow up”: Encountering illness in adolescence	54
“I don’t feel like it’s my body anymore”: How cancer alienates the somatic self.....	58
“Let the doctors do what they have to do”: Embracing passivity as a patient.....	61
“I just try to be a normal teenager”: Striving for normalcy amidst cancer	66
“It changes your relationships with people”: Shaping the social self with cancer	69

Chapter Four: Multidisciplinary Implications: Narrative as a Process and Product.....	73
Eliciting “Untold Stories”: Implications of Narrative Research Methods.....	75
Interactive Life Writing	75
Nonverbal Perception.....	78
Open-Ended Questions	80
Listening to “Unheard Lives”: Implications of Adolescent Cancer Narratives.....	82
Multimodality	83
Medical Education	84
Clinical Practice	86
Conclusion	89
Works Consulted.....	95
Appendices.....	109
Appendix A: Guiding Questions.....	109
Appendix B: Verbal Transcript.....	110
Appendix C: Written Narrative.....	112

Introduction

“I don’t think that I have ever really spoken about my cancer this much.”

—Andy, fifteen-year-old male

In a dimly lit hospital room, a fifteen-year-old adolescent paused his video games. Andy closed his eyes and told me about how it all started with a bloody nose that would not stop. He described his friends and family back home and the puppy he loves dearly, all the while speaking as if he were reliving each memory he recounted. He shared with me the simplicities and the intimacies of his life, from his hobby of baseball to the ways he had been affected by cancer. After an hour went by and our conversation drew to a close, Andy told me candidly that he did not think he had ever really spoken about his cancer that much.

Andy was one of the first adolescents I spent time with for the purpose of this thesis. Our conversation was guided by my questions about his diagnosis, his time in the hospital, and his whirlwind of emotions about cancer. As we talked, I learned more about his experiences through the memories he shared, the words he stumbled over, the deep breaths he took, and the moments of silence. When he confessed that this experience of talking about his cancer differed from any other, I was taken aback by the power of my presence. It dawned on me that such stories, told by adolescents with cancer, rarely have the space to emerge.

My thesis aims to give adolescents like Andy a space to express their experiences with cancer. For more than five years, I have been volunteering with pediatric oncology patients at the University of Michigan C.S. Mott Children’s Hospital. I have been getting to know these children and adolescents not only as cancer patients but also as individuals. I have become

dedicated to these youth and the cause of childhood cancer:¹ these experiences have largely shaped my own aspirations to become a pediatric oncologist. As I spent more time with these youth, I became increasingly curious about how children and adolescents make sense of their disease and cope with the mysterious complexity of cancer. I wondered about what emotions and feelings children and adolescents may experience, beyond their coping mechanisms and even beyond their diagnoses. I wanted to understand how cancer affected these children and adolescents, not only as patients but also as people.

My growing interest in the experiences of the ill led me to the literary genre of pathographies, characterized by literary scholar Anne Hunsaker Hawkins as “autobiographical or biographical narrative[s] about an experience of illness” (*Reconstructing Illness* 229). She introduced this term in 1986,² thus pioneering the study of a new autobiographical subgenre. Pathographies largely began to proliferate in response to the evolution and advancement of biomedicine, a Foucauldian term for Western medicine that accentuates the human body as its focal point (Gaines and Davis-Floyd 3). Psychiatrist George Engel criticized biomedicine for this very focus, claiming, “[m]edicine’s crisis stems from the logical inference that since ‘disease’ is defined in terms of somatic parameters, physicians need not be concerned with psychosocial issues which lie outside medicine’s responsibility and authority” (129). He chastised how biomedicine’s eager attention to the body marginalized and even blatantly delegitimized abstract experiences of illness. Engel called for a new biopsychosocial model of medicine to address both

¹ Pediatric, or childhood, cancer includes different kinds of cancers that primarily affect children and adolescents under the age of twenty-one. Since the phrase “childhood cancer” can be misleading when discussing adolescents with the disease, I will refrain from this identification and refer more specifically to “adolescents with cancer” throughout this thesis.

² Actually, Anne Hunsaker Hawkins *redefined* the term pathography. Sigmund Freud first used this word in reference to case histories, and physician-writer Oliver Sacks later described pathographies as narratives at the intersection of science and art. See Hawkins’ *Reconstructing Illness: Studies in Pathography*.

the patient and the disease, with special attention devoted to the “social, psychological, and behavioral dimensions of illness” (135).

In response to this shift in medical attention, physician and anthropologist Arthur Kleinman consciously and significantly distinguished between the words “disease” and “illness” to coin the term “illness narratives.” While the biomedical realm may primarily be concerned with pathological conditions of disease, Kleinman claims that illness represents the “innately human experience of symptoms and suffering” (1). Illness narratives extend from pathography to include expressions that exist outside of literature; these experiences are illustrated in works of art, embodied by dance movements, and, perhaps most prominently, even told in everyday conversation. Across media, illness narratives confront the complicated ways that we as human beings live with illness, looking beyond patient charts and lab results to explore how living with disease affects an individual. These works encompass stories, emotions, and experiences that may arise from ill health, which may or may not be explicitly about disease. In this thesis, I aim to gain insight into the experiences of adolescents with cancer through their illness narratives. Since these adolescent narratives are told through multiple modes, for they are not only written but also spoken and drawn, I will refer to them throughout these chapters as illness narratives.³

The phrase “illness narratives” begs the question, though: what characterizes these expressions of illness as narratives? Narratologist H. Porter Abbott’s definition of narrative as “*the representation of an event or a series of events*” can be helpful to understand the coherence and shape—or, significantly, the lack thereof—in such works concerning illness (12; emphasis in original). I define illness narratives as expressions about or around the experience of being ill;

³ Pathographies, on the other hand, are exclusively written works. They generally refer to full-length published books rather than more informal works of life writing about illness, such as those created by the adolescents in my research. See Hawkins, *Reconstructing Illness* xiv.

while these may be told from perspectives within and outside of the medical field, I focus on adolescents sharing their own personal cancer experiences. These adolescent narratives detail illness as an event, navigating through diagnosis, symptoms, and other experiences with and beyond cancer. These illness narratives bear different scholarly implications, especially for studies at the intersection of medicine and the humanities. The interdisciplinary field of medical humanities has largely been interested in “how the arts and humanities inform and elevate the work of healing,” especially through pathographies and other narratives about illness (Campo 1009). To clinically apply these studies, the nascent field of narrative medicine explores how illness presents itself as narrative in medical encounters and encourages health professionals to “acknowledge, absorb, interpret, and act on the stories and plights of others” (Charon, *Empathy, Reflection, Profession, and Trust* 1897). These overlapping and multidisciplinary scholarly arenas dedicate themselves to studying narrative presentations and representations of illness and demonstrate, I posit, the relevance of such works to narrative studies and medicine.

In addition, scholars in the social sciences,⁴ humanities,⁵ and health sciences have explored illness narratives,⁶ each contributing different perspectives on how illness narratives can effectively redefine traditional medical encounters. Narratives of illness can resist the oppression of the medical institution by functioning as works of *testimonio*, where “the [illness] narrator speaks not only for herself but for a group of marginalized individuals with similar circumstances” (Milner; brackets in original). Just as *testimonio* resists sociocultural forms of oppression, these works often challenge the conventional ways medicine objectifies the ill; they

⁴ See Arthur Kleinman, *Illness Narratives: Suffering, Healing, and the Human Condition* and Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics*.

⁵ See Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* and Ann Jurecic, *Illness as Narrative*.

⁶ See Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* and Sayantani DasGupta and Martha Hurst, *Stories of Illness and Healing: Women Write Their Bodies*.

highlight “the prejudicial construction of a normative culture’ rather than representing disease as a personal flaw or lack” (Beverly qtd. in Milner). In “a world where that voice is too rarely heard,” illness narratives were thus an “attempt, instigated by the body’s disease, to give a voice to an experience that medicine cannot describe” (Hawkins, *Reconstructing Illness* 12; Frank, *The Wounded Storyteller* 18). These expressions about illness sought to overcome the limiting, narrow scope of medicine by “assert[ing] the phenomenological, the subjective, and the experiential side of illness” (Hawkins, *Reconstructing Illness* 12). With similar goals, the field of disability studies repositions clinical experiences to contest the social repercussions of disability on identity. As a result, medical humanities, narrative medicine, and disability studies all use these narratives to trouble clinical experiences and resist the established hierarchies in medicine on a more systemic level. Together, these fields strive to restore humanity to the practice of medicine by appreciating the experiences of all those with illness or disability.

The interdisciplinary fields of medical humanities, narrative medicine, and disability studies have all taken a recent interest in life writing, or “writing that takes a life, one’s own or another’s, as its subject” (Smith and Watson, 2nd ed. 4). Life writing scholar G. Thomas Couser accounts for this academic fascination in life writing by explaining how the first-hand perspectives of those living with these conditions can illuminate experiences of illness or disability from within. He explains that since first-person life writing is “written from inside the experience in question, it involves *self*-representation by definition and thus offers the best-case scenario for reevaluation of that condition” (Couser, *Disability, Life Narrative, and Representation* 533; emphasis in original). While acknowledging the importance of these works, Couser also recognizes that “a prominent concern in much recent work on life writing has been who gets a life and who doesn’t” (*Recovering Bodies* 4). Couser raises an important question for

life writing studies: who has access to life writing and, as a result, to “get[ting] a life”? And, how may the act of life writing impose limitations on those who cannot narrate their own lives through traditionally available methods?

The (in)accessibility of life writing is especially of concern for the genre of illness narratives, where defining characteristics of illness or disability may hinder life writing abilities. Which conditions have gained visibility through life writing, and what others, by their very nature, may inevitably prevent such acts? Debilitating conditions like Locked-In Syndrome (LIS)⁷ or Amyotrophic Lateral Sclerosis (ALS),⁸ for example, have necessitated deviation from conventional life writing methods, often relying on technological capabilities instead. Yet disorders like autism or diseases like cancer have become ever-present in the media and, resultantly, in public consciousness. In 1993, for example, there were more illness narratives about cancer than about any other disease (Hawkins, *Reconstructing Illness* 70). This prominence seems to ring true even today, as a glimpse in a local bookstore may confirm. Not only are there people eager to write of these cancer experiences, but so too is there an audience eager to read about them.

Stories about breast cancer in particular, such as Audre Lorde’s *The Cancer Journals*, represent a subgenre that has exceeded in number the narratives of all other kinds of cancer. The sheer quantity of people who have breast cancer has certainly affected the explosion of these works, yet experiences with other types of cancers have hardly been communicated through narrative. Experiences of childhood cancer, for instance, have largely been left untold.

⁷ Jean-Dominique Bauby, a quadriplegic, “wrote” *The Diving Bell and the Butterfly* (1997) using the partner-assisted scanning method of communication. As his therapist spoke the alphabet out loud, Bauby used only the movement retained in his left eye to select letters and communicate.

⁸ Susan Spencer-Wendel typed her entire novel *Until I Say Goodbye: My Year of Living With Joy* (2013) with her right thumb in the Notes application on her iPhone.

When experiences of childhood cancer have been shared, they have mostly been captured from the perspectives of public relations personnel,⁹ health practitioners,¹⁰ or parents¹¹—but those who experience the illness themselves are rarely the ones telling these stories.¹² Narratives of childhood in general tend to be “written by adults, illustrated by adults, edited by adults, marketed by adults, purchased by adults, and often read by adults,” which suggests an exclusion of young voices (Jenkins 23). Recalling G. Thomas Couser’s concern about “who gets a life and who doesn’t,” I argue that adolescents affected by cancer hardly get a life through life writing.

There are some memoirs that recount personal experiences of having cancer as a child or an adolescent, but these books were not written in the present. Instead, these experiences tend to be retold by adults years after the fact. Lucy Grealy’s *Autobiography of a Face* (1994) looks back on how Ewing’s sarcoma (cancer of the jawbone) caused a facial deformity that contributed to her long-term insecurities and longing for love. In *Grace: A Child’s Intimate Journey through Cancer and Recovery* (2010), Melinda Marchiano traces her own journey in and out of cancer, surviving the disease and overcoming the eating disorder that follows it. Jason Paul Greer shares his experiences having cancer alongside close friends who did not survive with him in *Very Much Better* (2011). Nonetheless, these authors all confront cancer retroactively: “the adults who

⁹ Childhood cancer experiences have been reported in newspapers as well as by marketing endeavors for children’s hospitals. See Ann Dwyer, *Dexter Teenager with Inoperable Brain Tumor Asks Community to Help Charity* and The Children’s Hospital of Philadelphia, *Pediatric Cancer Patient Stories*.

¹⁰ In *Loving Hannah: Childhood Cancer Treatment from the Other Side of the Bed* (2011), Carol Glover writes about her dual perspectives as a nurse practitioner and a parent during her daughter’s childhood cancer treatments.

¹¹ Brooke and Keith Desserich journal about their daughter Elena’s experience with pediatric brain cancer in the book *Notes Left Behind* (2009). Rene Fesler navigates through her daughter’s encounter with cancer in *Alicia’s Update: A Mother’s Memoir of Pediatric Cancer* (2009).

¹² I only found one published book written by a child with cancer: Shannin Chamberlein’s *My ABC Book of Cancer* (1990). This book, however, was minimally publicized and is thus not easily accessible to a broader audience.

write them are removed from their childhood by time and, usually, place” (Douglas 21). These and other memoirs about childhood cancer reflect on similar experiences of cancer’s emotional toll and, albeit with variation, they all achieve ultimate resolution of some kind through successful treatment or fundraising for cancer research. Despite the presence of these retroactive works, there seems to be a void of narratives written by adolescents as they experience cancer.

I illuminate this void not to invalidate the accounts of those surrounding childhood cancer nor of adults who have lived through the experience. Rather, I propose that there may be a more timely and agentive way to gain insight into adolescent experiences of living with cancer. In this thesis, I contend that narrating the living rather than the lived experience of childhood cancer enables adolescents, regardless of treatment outcomes, to express their experiences with cancer from a youth’s perspective.

Current life writing that captures past childhood cancer experiences exemplifies “retrospective narratization,” which by nature may “distort the actual happenings (the history) of the illness experience, since its *raison d’être* is not fidelity to historical circumstances but rather significance and validity in the creation of a life story” (Kleinman 51). Although this purpose may not always be the case, retrospective narratization establishes temporal distance that makes these expressions more easily influenced by the purpose and context of their creation.

Autobiographies about childhood often “rewrit[e] of past childhoods as much as they reveal modern preoccupations about childhood”; similarly, available and expected forms for expressing illness are often recycled in retrospective illness narratives (Douglas 42). Sociologist Arthur Frank categorizes illness narratives based on these narrative tendencies and draws attention to how individuals may be especially inclined to rewrite the past to create restitution narratives: “[f]or the individual teller, the ending is a return to just before the beginning: ‘good as new’ or

status quo ante... this narrative affirms that breakdowns can be fixed” (*The Wounded Storyteller* 90). How might “the expectation that other people want to hear restitution stories” shape the narrative construction of illness (Frank, *The Wounded Storyteller* 77)? While Frank claims this narrative structure can be used “prospectively, retrospectively, and institutionally” (but he interestingly does not claim for its concurrent use), restitution narratives are notably prevalent in retrospective life writing where restitution has or appears to have been achieved (*The Wounded Storyteller* 77). In recalling and retelling of past experiences, how might life writers use restitution as a narrative technique to address the interests of their audience or even themselves? Due to the temporal distance between experience and expression, retrospective works tend to be more susceptible to conventional motifs for narrating the intimacies of illness.

Life writing about illness may indeed begin to give voice to untold experiences, but I argue that when only done retroactively, it may silence other individuals. Life writers about past illnesses are inevitably people who have outlived these conditions who society deems as “survivors,” but this requirement of retrospective life writing ignores other possible outcomes of cancer. Experiences that have been published through life writing represent the lives of adolescents successfully treated for their cancer and provided with the rare opportunity for publication. But what about adolescents who may not yet be labeled as “survivors,” those living with cancer whose futures may remain uncertain? Society has a tendency to “endlessly celebrate ‘survivors,’ while ignoring their equally valiant counterparts who did not survive” (Conway 18). In effect, this tendency alienates an entire subset of people from the life writing process and from publication opportunities, thus delegitimizing the experiences of those living with cancer. How can we give those who may not be “survivors” just yet (and may never be) the opportunity to tell their own stories and give voice to their own experiences? While retrospective life writing

provides its own valuable insight into illness, temporal distance often excludes the individuals living these experiences and silences their self-expression.

Current practices of life writing about cancer in adolescence are therefore inadequate, for they are told primarily from other perspectives or from a place of temporal distance. Reciprocal to these limitations of life writing, however, is the fact that academics devote little attention to existing works of youth and of illness, which intersect with the adolescent cancer narratives in this research. Despite their growing prevalence, pathographies and childhood autobiographies have scarcely been studied in the scholarly sphere. When they have, academics tend to discount the profundity of their claims/stories.¹³ Autobiographies of childhood face challenges in scholarly reception, for “[s]everal of these autobiographies use conversational language as a vehicle for their narratives, thus challenging established literary forms” (Douglas 171). Similarly, literary criticism was initially hesitant and somewhat resistant to embrace pathographies “because they are so rarely artistically developed and because they are so often latent rather than overt” (Hawkins, *Reconstructing Illness* 28). Able-bodied academics tend to presume that the impaired body of those with illness or disability also impairs narrative construction. Many hold misconceptions about a disabled or ill individual’s overall awareness of their self and surroundings. While scholars may demonstrate an aversion to narratives of youth and illness—albeit unknowingly, perhaps—based on assumptions of limited literary merit, these works remain uninspected and outside the scope of academia. As such, literary and cultural studies scholar Kate Douglas urges that autobiographies of childhood (and, I believe, illness narratives) need space to emerge and deserve scholarly attention, for they are “of significant interest to autobiography scholars and to media and cultural studies scholars, as well as those studying the

¹³ See Kate Douglas, *Contesting Childhood: Autobiography, Trauma, and Memory* and Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*.

sociology of youth” (172). Adolescent cancer narratives studied in this thesis thus provide an opportunity to advance scholarship about narrative, illness, and adolescence.

The current void of youth voices and corresponding lack of scholarly attention is disconcerting to me. It is problematic, I argue, not to listen to the unheard voices of those with illness, like adolescents with cancer. These voices can inform us about how individuals experience illness, which can illuminate the many illness experiences of a diverse population. These narratives, of adolescents who have hardly narrated their own lives, can reveal personal experiences of youth with cancer that may be overshadowed within the biomedical sphere. Since cancer is a living reality for so many adolescents, it is troublesome that adolescents with cancer have not had the opportunity to give voice to their experiences and intervene into discourse about narratives of youth and of illness.

Upon recognizing these untold stories, I have been motivated to create a space for adolescents with cancer to have the opportunity to express themselves and their lives through narrative. I began to wonder if literature, or rather narrative more broadly conceived, could play a role in the process of living with cancer. What if adolescents with cancer had the opportunity to tell their *own* stories? And what if others, from those who care for them to other adolescents with cancer, could receive and learn from these first-hand experiences?

I designed this interactive narrative research to give adolescents between the ages of ten and seventeen the chance to express, or even refuse to express, their own experiences living with cancer. I sat down beside these adolescents, and through verbal conversations, written texts, and/or visual representations, they shared with me their personal experiences with cancer. I provided participants with questions intended to guide but not limit our conversations. To increase the accessibility of narrative expression, adolescents could respond through any or all of

these media based on their personal preferences. I use the term *narrative* to include these multiple media of expression: transcriptions of verbal conversation, written word, and drawings. Most patients chose to speak with me about their experiences, and I encouraged those who were interested to fill the pages of a blank storybook however they would like. Some completed written and drawn narratives with me beside them while others took more time to complete them alone or at home. After I scanned their narratives, each participant was allowed to keep the original hard copy of their story.

While my research begins to devote scholarly attention to works that rarely receive it, I hoped to extend the reach of these narratives so adolescents with cancer could begin to fill the larger void in existing literature. As a result, participants have the opportunity to publish their stories through the University of Michigan Medical School; I am editing a forthcoming book, a compilation of adolescent cancer narratives collected in this research. I wanted adolescents to have the potential to share their experiences with a broader audience of more than just myself, but also with health care professionals, loved ones, and other youth with cancer.

Through the course of my research, I collected these spoken, written, and drawn narratives from twenty-five adolescents with cancer who were inpatients or outpatients at C.S. Mott Children's Hospital in 2013.¹⁴ Inpatients stay at the hospital anywhere from days to weeks at a time, some with scheduled admittances for treatment and others with unplanned visits due to unexpected concerns or complications. For clinic visits, blood tests, and infusion treatments, outpatients come to the hospital on a regular basis that varies from daily to biannually, depending on their cancer diagnosis and stage in treatment. Because adolescents often spend time as both

¹⁴ This is an ongoing research project. While I focus on the first twenty-five patient narratives collected, I have expanded the age range of this study to include patients ages eight through twenty-one. For the purposes of this thesis, newly collected narratives of child and young adult experiences will not be included.

inpatients and outpatients throughout the course of treatment, I will use these environmental contexts throughout my thesis primarily to situate narrative creation. Adolescents in this research are at different stages of living with cancer: some newly diagnosed with the disease, many undergoing treatment protocols that may range from months to years, a few in remission (no detectable cancer cells present after treatment),¹⁵ and several relapsed (cancer cells have returned following treatment). Together, these narratives illustrate the texture to life with cancer, a collective trajectory that is neither pre-determined nor definite but can begin to take shape through the insight of different adolescents.

My thesis explores how these adolescents express their illness experiences through writing, drawing, and speaking about cancer. Specifically, narrative illuminates how these adolescents conceptualize cancer and treatment, and how these understandings affect their developing sense of self, a concept I explore in chapter three. In the first chapter, I delve into my research methods and the ethical concerns that arise with adolescent involvement and researcher intervention. The narrative occasion my research presents and my prompting questions have guided the content and coherence of these illness narratives; I elucidate my methodology of collecting adolescent stories to consider my influence on these narrative constructs.

Since illness narratives “can function as indicators of how individuals define their illness and their identity, and ultimately the merging of the two,” the second and third chapters of my thesis enter into the narratives themselves to explore adolescent conceptualizations of cancer and of the self respectively (O’Hair, Scannell, and Thompson 419). In analyzing these narratives, I highlight similarities between how adolescents make sense of cancer and treatment as well as

¹⁵ I consider remission to be a part of the living experience of adolescents with cancer due to the frequency of follow-up visits for up to five years after treatment. Although there are no detectable cancer cells left and these adolescents are no longer being treated, these visits are required to ensure that an adolescent remains cancer-free and does not relapse.

how they construct an adolescent sense of self. My broader thematic observations are accompanied with close attention to the compelling, personal nuances of these narratives.

Chapter two explores how adolescents define cancer and chemotherapy, a treatment of toxic drugs to kill cancerous but also non-cancerous cells. How do adolescents understand this disease and treatment, and how do these perceptions affect their sense of self? While many defined cancer as a disease, elaborations often included but also challenged perceptions of cancer as uncontrollable, an abnormality, and even an evil. Adolescents sometimes struggled to distinguish between the effects of cancer and those of chemotherapy; I navigate through these understandings, ultimately to recognize their potential implications for adolescents with cancer.

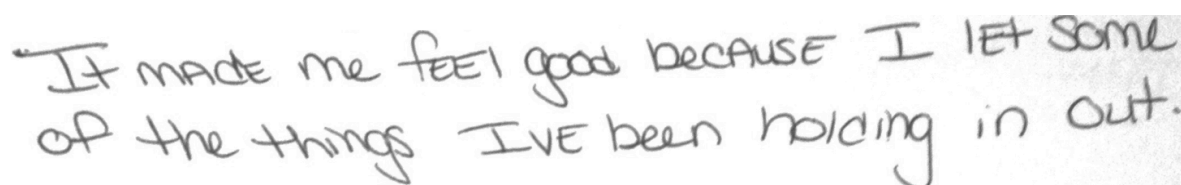
With these perspectives in mind, the third chapter inspects how experiences of cancer and chemotherapy affect an adolescent's sense of self. How does cancer at a time of coming-of-age influence the development of an adolescent self? These narratives reveal tensions of being an adolescent with cancer, especially the struggle to be a passive, compliant patient while becoming an autonomous individual with agency. These narratives illuminate how adolescents cope with illness and how they create a sense of self with cancer.

In the fourth and final chapter, I extend the broader implications of my research methods and of these adolescent cancer narratives. I examine what insight can be gained through interactive life writing, nonverbal perception, and open-ended narrative methods; the multimodal nature of these narratives bears relevance to the study of life writing and shares perspectives that can positively contribute to medical education and clinical practice. I look beyond this thesis to consider the impact my research may have on the interdisciplinary fields of medical humanities and narrative medicine as well as the broader fields of narrative studies and medicine alike.

The focus of this thesis, then, as reflected by the title, is two-fold. I devote my attention throughout these chapters to two fundamental aspects of my research: the untold nature of these stories as well as the unheard experiences of these adolescent lives. I envision this thesis as making room for adolescent agency and allowing these individuals, with personal and intimate experiences of their own, to enter into the discourse that surrounds their lives. These people have touched my life in ways I cannot fully articulate; my hope is that through this thesis, adolescents can begin to reclaim the stories of their lives, and we can give them our fullest attention.

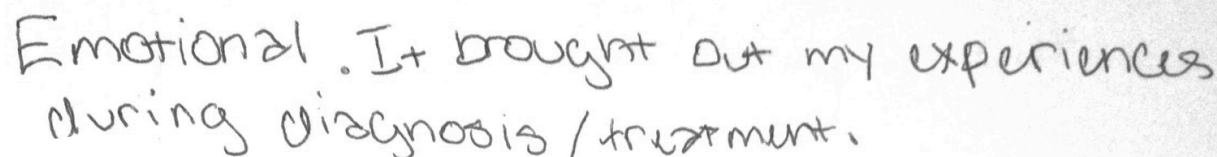
Chapter One

Methods and Ethics: Eliciting Adolescent Cancer Narratives



It made me feel good because I let some of the things I've been holding in out.

—Sixteen-year-old female



Emotional. It brought out my experiences during diagnosis / treatment.

—Fourteen-year-old male¹⁶

While many adolescents enjoyed having the opportunity to express some of their concealed feelings through this narrative activity, others found participation in this research to be a difficult and emotional experience. As exemplified above, narrative expression triggered varied responses of both pleasure and pain. Adolescent reflections about this experience, some positive and others less so, reaffirm a need for life writing methodology that strives to accommodate individual preferences. As I designed these interactive research methods, one primary question guided my decisions: how could my methodology for gathering illness narratives best attend to the range of experiences and the diversity of adolescents with cancer?

In this chapter, I delve into my methods to elicit adolescent cancer narratives and explore the ethical considerations that this collaborative creation process demands. I explain the logistics of narrative collection in the following two sections of this chapter, specifically with regards to participating adolescents and to my own role as a researcher. Within these sections, I recognize

¹⁶ After the narrative activity, adolescents completed a survey to reflect on the experience of narration. These were two responses from participating adolescents.

the implications of my methods on the narratives themselves. I also articulate how methodological transparency can inform our analysis of these adolescent cancer narratives.

Adolescents with cancer constitute a unique population that life writing scholar G. Thomas Couser would deem as “doubly vulnerable” (*Vulnerable Subjects* x). Vulnerability arises from the status of adolescents with cancer as youth and as patients. I delve further into the implications of this status in the “Adolescent Involvement” section of this chapter, but these instances of vulnerability establish a foundation for the many ethical considerations discussed in this chapter and returned to throughout this thesis. Adolescents are under parental authority for medical decision-making regarding treatment or procedures as well as for participation in this research (which I discuss later in this chapter). Consequently, they often experience a lack of autonomy within medical settings. In narrative creation, adolescent “inexperience as life writers” may also factor into their vulnerability (Douglas 173). Age, then, contributes multiple layers of vulnerability for these adolescents that affects the narratives they create.

Upon the presentation of disease, patienthood adds an additional layer of vulnerability that diminishes agency for adolescents (and others). In the hospital, adolescents may be subject to invasive procedures, strict drug regimens, and other restricting protocols. Their identity as patients demands passivity that has been innate in the “patient” label since its origination:

Etymologically, “patient” and “passive” come from [the] same root, the Latin verb meaning to suffer or endure. A “patient” is also the opposite of an “agent,” in that the latter acts and the former is acted upon. Those who are seriously ill in our society become patients in both senses—persons who must passively endure not only the disease but also what is done for and to them. (Hawkins, *Reconstructing Illness* 88)

Immersed within the medical realm, adolescents become susceptible to demands of compliance, a notion that also “connotes dependence and blame” for patients (Gould and Mitty 290). To be regarded as “good” patients, adolescents must comply with mandates enforced by medical professionals and often parents. With these inherently subordinating connotations of patienthood, I prefer to address these individuals as adolescents with cancer rather than as patients; I will only refer to them by their patient identity when I want to highlight their passive role in medicine.

The unique intersection of vulnerability in adolescents with cancer is fundamental to understanding these people and their narratives. The increased vulnerability of adolescents with illness, who constitute a population that is “vulnerable in two dimensions” (or perhaps even three due to limited narrative experience), reveals the urgency of granting them agency (Couser, *Vulnerable Subjects* x).¹⁷ Creating a space for adolescent agency to emerge can help to empower adolescents to even rise above this status. Who can better illuminate these experiences of vulnerability than adolescents with cancer themselves?

In order to best account for this increased vulnerability, my interactive methods depend on flexibility and adaptability: as G. Thomas Couser suggests, “[l]ife writing that is ethically ideal, then, might involve optimizing the autonomy of subjects, not merely ‘respecting’ it” (*Vulnerable Subjects* 23). It is not enough, according to Couser, to passively observe subject autonomy when conducting life writing research. Instead, researchers must strive to intentionally maximize subject autonomy rather than merely witness that which is naturally present. But how can research optimize the autonomy of especially vulnerable subjects? And what impact may

¹⁷ I want to emphasize that I cannot “grant adolescent’s agency,” for their agency is not mine to give. Current phrases for discussing agency are inadequate; they allude to broader systemic problems that conceptualize agency as something to be given to those without the power to obtain it themselves. Instead, I make an effort to use language that accentuates empowerment through the creation of space, thus returning the focus to the adolescent as an active agent.

such optimization, as opposed to just respect for adolescents, have on narrative works? These questions largely determined my research methodology, and this chapter examines how I addressed these concerns. While a common set of questions guided our interactions, conversations were tailored to each adolescent. I responded to these adolescents differently, giving them time and flexibility to construct their narratives and engaging with experiences they shared through follow-up questions. I embraced these individual encounters by striving to learn as much as I could about each individual and how cancer touched each life. By attending to personal preferences, I sought to do more than merely observe and respect autonomy but also to enable and optimize it throughout narrative creation. In line with these goals, I seek now to privilege and foreground these adolescent voices throughout this thesis whenever possible.

When examining similarly produced works of life writing, Couser cautions, “[t]he problem is that when mediation is ignored, the resulting text may be (mis)taken for a transparent lens through which we have direct access to its subject (rather than to its author)” (*Vulnerable Subjects* 38). I strive to recognize this mediation and address how it shaped these narratives. To optimize adolescent autonomy, I cannot overlook the impact of my methods on their creations. While I divulge the complexity of life writing as a methodological action in this chapter, my focus in subsequent chapters will be on the adolescent cancer narratives themselves. Illustrating the act of expression and its various repercussions can help, I believe, to contextualize these narratives and point to broader systemic limitations in place for youth with illness.

In the following sections, I explore two facets of my research methodology: adolescent participation and researcher intervention. As I examine adolescent involvement, I describe those who engaged in this research, the settings where this activity occurred, and the purpose and motivations behind participation. I then turn my attention inwards to inspect my influential role

as a researcher, particularly with respect to questions that guided narrative construction, emotional risks of interaction, and close analysis methods used in subsequent chapters. This methodology foregrounds my further analysis of how adolescents understand cancer, chemotherapy, and their sense of self. Throughout this chapter, I consider and question different effects of this methodology on participating adolescents as well as on my role as a researcher; these explorations establish a foundation for delving into the narratives in following chapters.

Adolescent Involvement

Participation

The approval process to conduct this research draws attention to the “doubly vulnerable” status of adolescents with cancer. This study (HUM00073552) could not occur without approval from the Institutional Review Board for the University of Michigan Medical School (IRBMED) and the University of Michigan Comprehensive Cancer Center Protocol Review Committee (PRC). IRBMED reviews all research with University of Michigan Health System patients and considers children to be “vulnerable subjects” because, as minors, they have not reached the legal age to provide consent. PRC reviews all research involving cancer patients; both institutional barriers aim to protect this especially vulnerable patient population. In order to gain approval for my research and collect these narratives, I established several protective measures that I discuss here and throughout this chapter.

To recruit adolescents with cancer for this study, health professionals such as physicians and child life specialists informed patients about my research. Relying on referrals may have skewed the sample of adolescents in my study, but widely available recruitment flyers and handouts made this opportunity accessible to a greater population of pediatric oncology patients.

Adolescent participation, however, demanded parental consent.¹⁸ This requirement no doubt shaped my sample because only patients whose parents were present and willing to consent could participate. That being said, not a single parent denied their child the choice to participate. Parental figures were overall enthusiastic and supportive of the mission behind my research and, if anything, some encouraged their children to participate. Many suggested that this activity would give adolescents something to do while waiting for doctor's appointments, lab tests, or infusion treatments, and that they would possibly even be able to help other adolescents with cancer in the process.

While parents overwhelmingly endorsed this research, some adolescents decided against participation: some due to a lack of interest, others delaying participation for when they felt better, and a few looking over the questions before choosing not to participate. One adolescent who had heard about the project from others was eager to get involved, but she began crying as she read the questions and ultimately decided not to participate. While these questions were conceived to be as minimally provocative as possible (see Appendix A for guiding questions; I discuss these later in this chapter), her reaction demonstrates the extent of variability in how adolescents responded to this research. Her emotional response also alludes to broader systemic inadequacies, for it seems as though clinical situations may not make space for sufficient reflection about cancer. Even as I sought to optimize adolescent agency whenever possible, this individual's reaction reminds us that protective barriers serve a purpose for this doubly vulnerable population. Under the circumstances, full agency may be unattainable for adolescents; nonetheless, I will demonstrate how intentions to optimize agency can indeed make a difference.

¹⁸ Parents completed an Informed Consent form while adolescents filled out an Informed Assent form. These forms were required by the IRBMED to ensure that adolescents (and also their parents) were knowledgeable about what participating would entail.

Settings

The settings of narrative creation also affected adolescent agency. These encounters took place in a variety of patient settings that adolescents with cancer typically occupy. I sat with inpatients by their bedsides in hospital rooms. I spoke with some outpatients in the waiting area, some awaiting check-ups in physician clinic rooms, and others as they received chemotherapy in the infusion clinic. While a number of adolescents completed their written or drawn narratives at home, all verbal conversations took place in these various clinical settings.

These sites certainly have affected narrative construction, even though it may be difficult to discern exactly how. As patients, adolescents are immersed in a clinical environment that constantly reminds them of the disease that brought them to the hospital. What difference, if any, does it make for an adolescent to write how “[i]t all really sucks” to go through chemotherapy as she is hooked up to an IV pole undergoing this very treatment? These sites (such as previous inpatient rooms or places where bad news was delivered) may, in unpredictable and unidentified ways, trigger memories of the past or remind these adolescents of the present. These settings inevitably influenced the stories adolescents chose to tell in the process.

In this clinical environment, “[s]ites establish expectations about the kinds of stories that will be told and will be intelligible to others” (Smith and Watson, 2nd ed. 69). Adolescents are likely accustomed to the direct and pointed questionings of health care professionals. By situating the adolescent as an authorial figure in places where their patient identity usually leaves them especially vulnerable, this activity may lead adolescents to think these narrative expressions are only about their cancer rather than their lives as *individuals* with cancer. They might assume that questions must be answered without tangential anecdotes or irrelevant facts. While some adolescents focused their narrative expressions solely on cancer, others chose to tell

me about how they liked coffee or were excited for an upcoming concert. Clinical surroundings clearly influenced the amount and the kinds of information adolescents chose to share; limited conclusions can be drawn about the impact of these settings, but more importantly, they help us to contextualize the narratives created. These sites potentially reminded adolescents that the cancer experiences they narrated remain a living reality. Throughout this thesis, I will describe the surroundings for each detailed anecdote I share; I will use the past tense to describe verbal conversations that I had with these adolescents and the present tense to analyze the written and drawn narratives that they have created. This disclosure is my attempt to enhance transparency and provide greater access into the circumstances of narrative creation.

Within these settings, different individuals were present as witnesses, constituting an immediate audience that was involved in narrative creation to varying degrees. Since parental consent was required for adolescent participation, I allowed those who wanted to be present during these interactions to do so. Some encounters took place in the presence of parents, siblings, extended family, and/or close friends. Others were one-on-one, either by coincidence or because parents preferred to give their children privacy. Some quietly observed how this discourse ensued while others inserted their voice into spoken adolescent narratives. My physical presence as well as that of others raises questions about how best to optimize adolescent autonomy. If a parent chimes in to the verbal conversation, should I ask them to let the adolescent speak? Or should I allow such intervention to persist? Ultimately, which action best preserves an adolescent's agency within IRBMED constraints to protect "vulnerable subjects"? I chose to straddle the middle ground between these extremes. To minimize difficult scenarios, I emphasized that this research was about how *adolescents* express their experiences. In most cases, parents and others remained silently present. Those who spoke encouraged adolescents,

reminding them about thoughts or forgotten instances that may be relevant. I found that accepting natural parent-child dynamics while emphasizing my own interest in adolescent perspectives seemed to be an optimal balance of enabling agency within research constraints.

While I took note of those present at each patient encounter, it is hard to say for certain how these individuals and their various relationships to adolescents affected the narratives. How might the dynamics of such intimacies affect ideas voiced, words written, or images drawn? An immediate audience shapes expression in both visible and unidentifiable ways. Although these considerations may not have simple answers, they shed light on other ways that adolescent agency may be challenged or suppressed within the medical realm.

Purpose

An important way that adolescents exerted agency is by choosing whether or not to participate. Why would adolescents get involved in narrative research, and how might these motivations factor into the works they create? The way I described my research alludes to some of the main reasons adolescents decided to participate. I told interested adolescents and their parents that I was doing a research project about how children and adolescents with cancer write, draw, and speak about their experiences. I also informed them that, if they were interested, adolescents would have the opportunity to publish and share their personal stories; participating could be a way to help other adolescents with cancer.

The reasons why adolescents chose to participate provide insight into whom their narratives may target. Altruism was a driving motivation for many adolescents, one that emphasized the implied audience of others with cancer that would receive their narratives. Some adolescents who were initially hesitant were moved to participate by this very notion. The publication opportunity enabled adolescents to imagine a broader audience for their narratives,

one that could include health professionals, family, and friends that may not be immediately present but could encounter their narratives in the future.¹⁹ Most importantly, this implied audience explicitly includes other adolescents with cancer, individuals who share a cancer diagnosis and are, as Jason Paul Greer put it in his memoir, “on my side of the needles, on my side of the sickness” (96). Knowing that others with cancer might receive these narratives, what experiences would adolescents share and what emotions may remain untold? Many were honest about their dislike of cancer and the harmful side effects of treatment, likely believing that others would share these sentiments. Yet it seems as though more intimate details about living with cancer may have remained concealed to protect this implied audience. Maybe adolescents felt uncomfortable sharing depressed thoughts to others who may be in similarly dismal situations, especially if such expressions might also alarm an immediate audience. Implied audiences may not always be discernable from the narratives, but it is likely that they affected these expressions in subtle, and sometimes not-so-subtle, ways. Enabling adolescents to address a variety of audiences helped to optimize their agency in the narrative creation process.

From adolescent requirements to hospital settings to motivations for participation, this narrative approach prioritizes adolescent agency whenever possible in the context of participant involvement. With these factors in mind, the following section investigates how my role as a researcher has influenced narrative creation.

¹⁹ Creating a corpus of written and drawn narratives for publication is an end goal of this project, but my research is also informed by spoken word and extratextual details of narrative creation.

Researcher Intervention

Questions

In this narrative activity, I provided a series of guiding questions to support adolescents who may prefer direction in expressing their personal experiences with cancer (see Appendix A for these guiding questions). Since “the content and structuring of questions can either facilitate or constrain the life of narratives,” I developed open-ended questions to better enable adolescent agency (Gunaratnam 49). I specifically crafted questions to optimize, or at least promote, autonomy by prompting and encouraging narrative expression. Even though these questions did not have to be followed nor explicitly answered, most adolescents who engaged in verbal conversations preferred to have this structure as they narrated their experiences and emotions (see Appendix B for sample verbal transcript). Written and drawn narratives, however, were influenced by the questions in more variable ways. Some were formatted around the prompts: one mirrored the question-and-answer structure (see Appendix C for sample written narrative), another color-coded bullet points with different topics. Others deviated more significantly from the questions by addressing some common topics about treatment or the hospital and omitting others about advice. Adolescents needed different amounts of guidance in narrative creation, as exemplified by the various ways that they relied on these questions.

With these guiding questions, my approach encourages autobiographical acts of “collaborative life writing” (Smith and Watson, 2nd ed. 240). In these encounters, my questions influenced content and coherence, which prompts me to wonder: how have I intervened into these narratives by eliciting these stories? The questions I have used to encourage these narratives have shaped the stories told, the words written, and the images sketched. These questions largely directed our exchanges, steering adolescents as they addressed the often-

uncharted territory of their past, present, and future cancer experiences. In a sense, with my voice intervening to guide the narrative sequence, I inserted myself into these autobiographical works. Since these guiding questions represent my presence within these narratives, I must acknowledge my range of emotions, such as my expectations, surprises, disappointments, and appreciation. Throughout narrative analysis in the following chapters, I will describe my own reactions whenever pertinent. Just as I was affected by witnessing adolescents express themselves, my responsiveness likely influenced narrative creation. Some of my feelings also allude to larger systemic problems with how we as a society understand adolescents with cancer, which I will discuss in greater depth throughout this thesis.

Risks

The multiple layers of vulnerability in adolescents with cancer impose fresh challenges on narrative research methodology. In order to receive IRBMED approval, I had to minimize the risks of participating: I claimed that none of the questions are intended to be challenging (although, as I have mentioned, they were sometimes sensitive), participation is voluntary, and patients can withdraw at any time if they feel uncomfortable. While this explanation meets the IRBMED requirements for ethical research, life writing research presents emotional risks of its own for participating adolescents.

Perhaps one of the most profound aspects of my research approach is merely the magnitude of what I ask of my participants. In a sense, my research asks adolescents with cancer to expose themselves emotionally, to willingly put themselves in a situation that renders them as especially vulnerable. For many of these adolescents, cancer may encompass some of the most traumatic experiences in their lives. By asking them to confront cancer, to find the words to express how they feel and to remember sometimes daunting life events, I am asking them to

open themselves up to additional emotional risk. To illustrate the extent of this tall order, I find it best to share a personal vignette from my interactions with a particular patient.

A fourteen-year-old adolescent and his mother were excited about my research project, enthusiastic about the activity and eager to help others with cancer. This outgoing adolescent began to boldly respond to my questions. But when I asked him how cancer made him feel, he slowly began to break down. His quiet sniffles slowly escalated into tears. I waited, then asked him whether he would like to stop and he said no. When asked if he would like to move on to the next question, he shook his head and took a few moments to gather himself. He struggled through the rest of the activity with a soft, feeble voice, never quite regaining composure.

I had known from the outset of this research that such an emotional reaction was indeed quite possible. His crying was accompanied by my own ethical contemplations about how to appropriately respond to the suffering of another human being. And I realized that in this moment, I had caused this anguish. This immediate pain was something I had triggered, maybe even provoked. In the aftermath of our encounter, I was overwhelmed by my own ethical questions. Did I do something wrong? Could I have better handled the situation? Eventually, I came to the realization that my presence had enabled this emotional expression.

To prepare for such risks, I informed participants that health professionals would be told about any unexpected or adverse responses to this activity. Emotional reactions became a way to identify adolescents who may be struggling to cope with their disease. These triggered responses provided an opportunity to enable better care for this adolescent: clinical care to face underlying psychological challenges, narrative care to witness and attend to his needs, and agentive care to potentially enhance the control that he feels over his life and his cancer. This adolescent's emotional response enacts his agency, embodying it in his tears. My research opened an arena

for him to emotionally express himself in a way that may be constrained within clinical and everyday narrative contexts. This vignette, I believe, illustrates the difference between optimization and encouragement of vulnerable subject autonomy. My methods revolve around preserving adolescent agency and, in a sense, enabling this very divergence. Recognizing the various ways that individuals responded to this research provides an important foundation for understanding the complex and occasionally divergent narratives that adolescents shared.

Analysis

For collaborative narratives such as these, “prompting questions, translations of the autobiographer’s oral speech, and revisions are often invisible in the final text” (Smith and Watson, 2nd ed. 67). With this “invisible intervention” in mind, the transcription process plays an important role in affecting narrative creations. In creating textual representations of verbal dialogue, I used punctuation to portray the nuances of spoken language such as stumbled words and deep breaths. When I quote our verbal exchanges, I will only omit these details when they seem irrelevant to context or to my argument.

Before delving into the narratives in the following chapters, I would like to elucidate my approach to analyzing these works. These analysis methods largely stem from my motivations for this project: I study these narratives by highlighting shared elements while paying attention to the idiosyncrasies of each work. With my own clinical inclinations, I wondered how adolescents would make sense of cancer, a disease defined by medical terminology. As someone who regularly spends time with these individuals, I hoped that narrative would help me to better understand how experiences with illness personally affect these adolescents.

As I encountered these works, I was struck by the resonances and dissonances across these narratives. Due to the sheer volume of narratives that I collected (twenty-five altogether), I

devote my attention to adolescent experiences and perspectives as expressed in excerpts of their narratives, which enabled me to better honor the breadth and depth of this collection.²⁰ I have gravitated towards the commonalities and individual characteristics across these works through a thematic analysis. I find the literary term “theme” helpful; it generally represents the central focus or “subject” of a singular text, but I repurpose the word to represent recurring ideas that span an entire body of adolescent cancer narratives (“Theme”). Although I agree that “no matter how rigorous our research methods and practices are, narrative analysis is always partial and provisional,” I believe a thematic close analysis most aligns with my goals for this thesis to optimize adolescent agency (Gunaratnam 57). In the chapters that follow, I will interpret both shared and personal facets of how adolescents experience cancer, which will provide greater insight into their unique perspectives.

Throughout this chapter, I have emphasized my goal to optimize the agency of a vulnerable population of adolescents. I have fully disclosed, insofar as is possible and relevant, my approach to eliciting adolescent cancer narratives. In anticipation of analyzing the narratives themselves, I have strived to encourage a better understanding of my research methodology and the context of narrative creation. This chapter has outlined a number of ethical considerations inherent in my methods, from various immediate and implied audiences of these narratives to the emotional responses that my research sometimes triggered. With these factors in mind, I turn my attention in the following two chapters to explore how adolescents conceptualize cancer and, furthermore, their own sense of identity.

²⁰ To increase the accessibility of life writing, I encouraged narrative expression through writing, drawing, and speaking; therefore, I will evaluate each expression with the same analytical weight.

Chapter Two
“Bad Blood Cells, Good Treatment”: Conceptualizing Cancer and Treatment

Bad blood cells
 • Good Treatment

—Ten-year-old male

Upon diagnosis, adolescents are given a new identity that defines them as individuals “with cancer.” Cancer becomes, at least for the time being, an inextricable component of who they are. In an inpatient hospital room, I asked the adolescent quoted in the epigraph of this chapter about what his cancer looks like and what he likes about cancer. This adolescent condemns cancer and praises treatment, presenting them as polar opposites in a dichotomy of “bad blood cells” and “good treatment.” By identifying treatment as something he likes about cancer, this adolescent recognizes that treatment is integral to his experiences with the disease. How adolescents experience cancer is largely affected by the ways that they perceive the disease as well as its treatment. These definitions of cancer and chemotherapy thus establish a foundation for understanding how adolescents make sense of a newfound identity with cancer.²¹

Most adolescents in this study recognized cancer as a disease, but many confessed that they did not know how to further explain their conditions. Even though some recalled the medical terminology of their particular diagnosis, such as Acute Lymphoblastic Leukemia (ALL), a cancer of the blood cells, most chose to describe their personal experiences of cancer’s symptoms. Interestingly, the use of medical and personal vocabularies to define cancer hardly

²¹ Chemotherapy is not the only treatment that adolescents undergo for cancer (others include radiation, surgery, or a combination). However, a majority of adolescents in my research focused on the side effects of chemotherapy when describing their treatments. In this chapter, I will be using these terms synonymously.

overlapped; those who defined cancer by their diagnosis, for example, did not further explain it on a personal level. Others who tried to describe cancer in their own words were honest about their struggles to do so in terms other than the label of disease. In this chapter, as I note the prominent ways that adolescents define cancer—as an excessive loss of control, an impairment and a disability, and an evil—I also draw attention to conceptualizations that best challenge and resist these themes. In complicating these apparent trends, I recognize that variation remains, despite similarities across adolescent understandings. If my methodological goal has been to optimize adolescent agency, as I explained in chapter one, my analysis must embrace these diverse perspectives of cancer, as is the focus of this chapter.

Moreover, to regard these experiences with cancer holistically, I also look at how adolescents cope with treatment. Adolescents make sense of treatment in similar ways to how they understand cancer. Many labeled their treatment as chemotherapy but were uncertain about what it does in the body beyond its unintentional side effects. Because cancer and treatment largely determine an adolescent's experiences as well as (potentially) mortality, the ways that adolescents conceptualize cancer and treatment inevitably affect how they create selfhood with cancer, a concept I briefly mention in following sections and delve into in the next chapter.

In exploring how adolescents make sense of disease and cope with treatment, I have found that there are close parallels between how adolescents conceive of cancer and chemotherapy. These similarities may be surprising and perhaps counterintuitive, yet the ways that adolescents perceive cancer and chemotherapy resemble one another, thereby revealing potentially ambiguous understandings of both. These experiences are central to adolescent narratives and identities; this chapter investigates how cancer and treatment are characterized in these narratives as uncontrollable, how they are understood as impairments and disabilities, and how they are

ambiguously conceptualized as both a blessing and a curse. In each of the following sections, I also highlight the ways that adolescent perspectives may contradict these prominent themes, for each individual understands and experiences cancer and chemotherapy differently.

“Can’t really control it”: Cancer and chemotherapy as uncontrollable

Although the adolescents who participated in this research all have cancer, their diagnoses represent many different kinds of cancers. Due to my small sample size of twenty-five, I consider their experiences collectively instead of focusing on differences that arise from individual diagnoses. Nevertheless, “[c]ancer is not one disease but many diseases. We call them all ‘cancer’ because they share a fundamental feature: the abnormal growth of cells” (Mukherjee xvii). Many divulged this diagnostic characteristic of cancer. What fascinated me, however, was that this scientific classification of the disease extended into adolescent experiences of illness.

A number of adolescents associated cancer with a loss of control: on a fundamental cellular level and as a more abstract and pervasive component of life with illness. Even outside of medical language, cancer has often been described by its “unregulated, abnormal, incoherent growth,” which is how many of these adolescents also defined the disease (Sontag 62). Zack, a sixteen-year-old, said matter-of-factly that cancer is “[j]ust something that happens. Can’t really control it.” By ambiguously referring to cancer as “it,” Zack allowed multiple dimensions of the disease to become uncontrollable: the cause of cancer, the growth of cancer cells, and its overall progression. In addition, fifteen-year-old Jacob explained how these cancer cells “couldn’t do what they were supposed to by themselves. I...I had cells that were growing twice as fast.” When these cells begin to grow abnormally and without pause, they are no longer an accepted part of the self. Cancer estranges cells, transforming them into what one adolescent described as

“something you probably got to get rid of.” Although cancer cells may be an unwanted part of the body, their impact extends beyond the physical self to permeate into one’s mind and emotions. How does understanding cancer as a disease of inadequate, unmanageable cells affect adolescents with this diagnosis? Some observed how this loss of control was paralleled by a loss of order in their own lives. Upon diagnosis, one adolescent described how “I felt like I had no control, and...felt...felt like I couldn’t change what happened.” The uncontrollability of cancer appears to disrupt her sense of agency. Cancer disempowers this adolescent, leaving her helpless.

The loss of control imposed by cancer not only challenges an adolescent’s agency but, as several adolescents were also aware, the disease endangers their own lives. When I asked fourteen-year-old Heather what cancer is, she began by defining it on a cellular level but concluded with its broader potential consequences: “Umm... so all your cells get taken over with...it’s kind of a hard question, I don’t really know either. I don’t think anyone really knows, it’s just... cells that can kill you, take over your body.” Since cancer can be life threatening, those diagnosed grapple with uncertainty about whether cancer will take their life, an extreme yet plausible fate. For those with cancer, these “uncertainties about the future often provoke a profound sense of loss of control” as death becomes real (Beale, Baile, and Aaron 3629). A thirteen-year-old adolescent, who was in remission at the time, was temporally detached from his cancer and could be straightforward about the grim possibility of death. “Oh, it’s something that you can die from,” he said firmly. Since adolescents are just coming of age and beginning to claim responsibility over their lives, this life-threatening aspect of cancer can be especially frightening.

Despite chemotherapy's attempts to restore order amidst the disorder of cancer, many adolescents found treatment to be overpowering and disorienting, just like the disease it targeted. Many described feeling "weak," "tired," and "sick." Fourteen-year-old Tamia writes:

Sometimes it even makes
my Emotions go all over the
place. One minute I'm
happy, the next I'm upset,
and crying, or very mad
and annoyed.

Chemotherapy, she claims, is the cause of her unpredictable emotions. Treatment leads to emotional entropy, a chaotic fluctuation of feelings. If chemotherapy is administered to get rid of cancer cells and restore balance though, how do adolescents understand the interruption imposed by its side effects? If treatment eliminates out-of-control cancer cells, then shouldn't it restore some semblance of control to one's self? As adolescents recognize the need for treatment and suffer from its side effects, the struggle to make sense of this paradox recurs in their narratives. Chemotherapy *may* (although not always) eliminate unregulated cancer cells, but side effects of treatment unleash an alternate level of chaos. These conflicting effects of order and disorder lead adolescents to form varying opinions towards their treatments.

“Disavantange”: Cancer and chemotherapy as impairments and disabilities



The word "Disavantange" is written in a cursive, handwritten style using pink marker. The letters are connected and have a soft, slightly blurred appearance, suggesting it was written on a white surface like paper or a chalkboard.

When speaking with me in his hospital room, this ten-year-old defined cancer as a “disavantange,” explaining how “you won’t be able to do like a lot of things that other kids do.” While he writes about a disease of “bad blood cells” (as quoted in the epigraph of this chapter), he looks beyond this biological condition to recognize how it more generally prevents him from doing “things that other kids do.” A number of adolescents alluded to these extended effects, which characterize cancer as both an impairment and a disability. In the field of disability studies, “[i]mpairment is distinguished from disability. The former is individual and private, the latter is structural and public” (Shakespeare 268). As I expected, many adolescents felt negatively towards their cancer and treatment because of the physical limitations that they imposed on their bodies and hence, their selfhood. At the same time, several were aware of the broader effects of cancer and chemotherapy, such as the social barriers triggered by diagnosis and treatment, and how these limit their social identity.

Most adolescents discussed the various impairments that treatment, rather than cancer, imposed upon them. Fifteen-year-old Lexie, for example, seemed attuned to the irony of treatment as an impairment when she told me, “more than anything, it’s the chemo that makes me miss out on life experiences not the actual cancer.” To eliminate the presence of cancer cells, chemotherapy must disable normal bodily functions through physical side effects of its own. Another thirteen-year-old described how “the vincristine [a drug] I...I can’t even walk with my heels. And the...chemo...my eyes will start hurting.” To him, chemotherapy was immobilizing

and maybe even blinding. Tabitha, a thirteen-year-old, also felt this halting effect, explaining how “[c]hemo made you just not want to move at all, didn’t make you feel good at all.” These adolescents experienced the debilitating effects of chemotherapy, which stripped them of everyday capabilities and individual autonomy.

On a broader scale, adolescents also recognized that cancer and chemotherapy were socially disabling. I asked Tabitha what she would like the adults in her life to know about what it is like to have cancer, and she said, “It’s really tough. A lot of people might look at you like you’re different and it kinda hurts when they do.” For Tabitha, experiencing the stigma of cancer has harmful consequences, as “staring registers the perception of difference and gives meaning to impairment by marking it as aberrant” (Garland-Thomson 190). Disability studies scholar Rosemarie Garland-Thomson describes how “[a]t the same time, staring constitutes disability identity by manifesting the power relations between the subject positions of disabled and able-bodied” (190). Tabitha feels degraded when others look at her differently because their perceptions remind her of the “abnormal” disease that inhabits her body. Beyond appearing different, another seventeen-year-old was concerned about how people would treat her. “I don’t want people to treat me differently because of it,” Celeste explained to me. “It doesn’t define who I am, it’s just something that I have, just a part of me, you know?” Just as some people understand autism or other neurodevelopmental disorders,²² cancer becomes a component but not all-consuming part of Celeste’s identity. Celeste claims cancer as part of her self, advocating that she is more than her cancer.

²² See Pier Jaarsma and Stellan Welin, *Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement?*

As cancer makes adolescents feel disabled by their difference, undergoing treatment also distances adolescents from those without cancer. Lexie, for example, is struck by the social consequences of her treatments:

The one thing I hate the most though is the time spent away from friends. You may find yourself alone at times because your friends don't ask you to hang out.

Although treatment made her feel “icky and tired,” she is more hurt by the isolation it imposes on her life. She cautions others about this part of being treated, explaining that friends often do not know how to react in response to one’s treatment. Chemotherapy alienates Lexie, not only differentiating her from others but also separating her from the community in which she once seamlessly belonged. Adolescents are especially vulnerable and stripped of their agency by the physical and social consequences of cancer as an impairment and as a disability.

“It’s scary and it’s awesome”: The evil and the good of cancer and chemotherapy

When I asked Jacob what he would say or do if cancer was a person, he said, “in some ways I’d thank it, and in some ways I’d hate it.” As an outpatient in remission, Jacob had just come in for a doctor’s check-up appointment. After speaking with fifteen adolescents by this time, I was stunned to hear him so blatantly appreciate his cancer. Jacob explained how cancer is “scary and it’s awesome, at the same time,” claiming that the disease, albeit intimidating, was still a fortune. Although I was initially surprised to hear such a positive outlook on cancer, Jacob was not the only one to praise the disease. Similarly, adolescents had both positive and negative opinions towards chemotherapy. Different vantage points reflect the various ways that these

adolescents are affected by their disease and treatment. Each individual comes to make sense of their cancer and identify around it in their own way.

Since I was present to witness these narrative expressions and hear Jacob express gratitude for his cancer, I must recognize my own positionality as a researcher and situate where my surprise about his response came from. I do not have, nor have I ever had, cancer. I have not had a sibling, close friend, or loved one with this disease in their youth. My exposure to adolescents with cancer has been somewhat marginal, as an observing and participating volunteer. I realize that my surprise at this optimistic perspective is a somewhat demeaning and ignorant reaction to an honest expression; even though I knew adolescent perspectives on cancer would vary, this awareness did not change how I, at the time, emotionally responded to unexpected opinions.

Despite my initial shock about Jacob's positive outlook, favorable perspectives of cancer can indeed be useful. The move to embrace rather than dissociate disability from one's identity has been an impetus for the field of disability studies, since "[t]he placement of disability as a valued concept in identity formation has largely been the result in the shift from the medical to a social discourse on disability" (Johnstone). An affirmative outlook resists "[t]he erroneous idea that disabled people cannot be happy, or enjoy an adequate quality of life," instead redefining disability as "a positive personal and collective identity" (Swain and French 573, 571). This understanding of disability encourages us to question: what effect does a positive perspective of cancer have? An appreciative point of view can empower individuals like Jacob within a society that perpetuates opposition and aversion from illness, disability, and individuals with these conditions. Jacob accepted the inevitable impairments of illness and valued what he could about his condition, which allowed him to find contentment and better cope with cancer.

Jacob's conceptualization pinpointed illness on a spectrum of good and bad, which is not an entirely novel way of comprehending disease. According to literary scholar Anne Hunsaker Hawkins, the "'mythogenic' habit in Western culture of thinking in oppositions and in contrarities" has shaped other thought processes such as the conceptualization of illness (*Reconstructing Illness* 62). She traces these dichotomies to show how "[h]ealth seems to fit in naturally with those entities that protect and nurture humanity—light, life, and good; disease, correspondingly, belongs with darkness, death, and evil" (Hawkins, *Reconstructing Illness* 62). Aligning with this binary, perspectives on cancer tend to antagonize the disease and praise chemotherapy, but not without affecting the individuals with the condition.²³ In studying metaphorical representations of illness, literary scholar Susan Sontag cautions, "[n]othing is more punitive than to give a disease a meaning – that meaning being invariably a moralistic one" (*Illness as Metaphor* 58). What repercussions, then, do moralistic conceptualizations of cancer and chemotherapy have on those living these experiences?

Despite traditional binaries for conceiving illness, these narratives suggest that for adolescents, disease and treatment may not "seem to fit in naturally" with the polarities of good and evil. How do alternative perceptions of cancer and chemotherapy complicate this prominent dichotomy and affect adolescents? In these narratives, adolescent perspectives about cancer and chemotherapy were sometimes conflicting. While some strongly despised cancer, others found aspects of the disease that they valued. Despite disliking chemotherapy's detrimental side effects, as I have shown in previous sections of this chapter, many adolescents still praised treatment. By complicating traditional understandings of cancer and chemotherapy, these divergent views can shape adolescent identities in both common and unconventional ways.

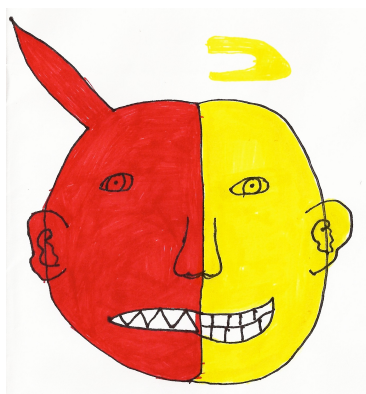
²³ See Susan Sontag, *Illness as Metaphor*.

Many adolescents, for example, resorted to common battle imagery to illustrate their relationships with cancer. Just as Sontag identified battle language in adult representations of cancer in 1978, language used by adolescents to communicate about cancer remains violent (and so too does the treatment): “[t]here is the ‘fight’ or ‘crusade’ against cancer; cancer is the ‘killer’ disease; people who have cancer are ‘cancer victims’” (57). How do such metaphors influence the ways that adolescents understand cancer and chemotherapy, and themselves? When I asked adolescents what they would say or do if cancer was a person, many resorted to violence and wanted to “beat it up” or “kill it.” Some wanted to create distance to separate themselves from their cancer and more passively “make it leave” or “keep it out.” For adolescents who “survive” cancer, those successfully treated and in remission, these ways of thinking about illness as a battle to be won can be especially strengthening.

But how does this language affect adolescents with poor prognoses, or those with cancer that relapses even after treatment? Many adolescents experiencing cancer evoke battle imagery to boldly take responsibility for the course of their treatments, but such antagonizing language can have damaging effects on an adolescent’s self-esteem if and when treatments fail. The practice of invoking battle responses is, then, inherently flawed, for “[o]stensibly, the illness is the culprit. But it is also the cancer patient who is made culpable” (Sontag 57). If adolescents consider cancer as a part of themselves, especially since the disease arises from normal body processes gone astray, then what does it mean for these individuals to be at war with themselves? Sontag describes how, incidentally, “conventions of treating cancer as no mere disease but a demonic enemy make cancer not just a lethal disease but a shameful one” (57). Failed treatments or metaphorical loss immediately locate blame within the adolescent patient; combat becomes an inevitably problematic way to perceive cancer when the site in question is one’s body. Battle

imagery thus empowers but also burdens these adolescents, often depending on where they are in the context of treatment. As this variability reaffirms, assuming the applicability of battle language proves woefully inadequate for diverse adolescent populations.

Fifteen-year-old Jacob's experiences with cancer and chemotherapy were not as straightforward as battle language may suggest. In a quiet, isolated corner of the waiting room, as he told me about his experiences with cancer, Jacob also started to draw:



Cancer is half and half.
It can be the devil, or
~~it~~ it can be an angel. It
all depends on your
attitude.

He first defines cancer with a bifurcated identity, as “half and half,” part evil and part good. Immediately after objectifying cancer as an “it,” Jacob personifies cancer to the extremes of “devil” and “angel” and transforms the disease into a being. He elaborates on this inherent duality, claiming that cancer’s identity relies solely on an adolescent’s perspective. Even though Jacob hated treatments, he appreciated the once-in-a-lifetime opportunity to meet professional athletes because of his cancer. Jacob’s notion that “[i]t all depends” seems to represent his personal belief that his attitude defines, or even defies, cancer.

In describing cancer’s identity as fluid and malleable, Jacob presents both a demanding and liberating charge that imposes the power to define cancer upon the adolescents who have it. He encourages adolescents to take control over this disease of uncontrollable cells. But at the same time, he burdens youth with responsibility over their cancer. How are those experiencing

cancer as an illness and a disability affected when their bad attitude is to blame? “Disability is presented primarily as a ‘problem’ that individuals must overcome,” a problem for which these adolescents are suddenly held accountable (Couser, *Signifying Bodies* 34). Jacob challenges adolescents with cancer to simply embrace a positive attitude, and he seems to advocate that “overcoming it [cancer] is a matter of individual will and determination” (Couser, *Signifying Bodies* 34). By defining the disease in terms of good and evil, Jacob imposes empowering duty upon adolescents; he evokes a sense of morality through the angel and the devil figures, of right or wrong ways to perceive cancer. What does this moral responsibility mean for adolescents who are not in remission like him, ones who may despise everything about their cancer? For those who understand cancer as an evil, is it their responsibility to define cancer more positively? Jacob charges others to redefine cancer and value what good may come out of these experiences, but such claims demand a universal coping mechanism and potentially undermine how individual adolescents come to terms with cancer.

Although being in remission surely influenced Jacob’s perspectives on cancer, another adolescent in treatment expressed similar sentiments about the good in the disease. I was taken aback by how Tabitha defined cancer when speaking to me at an outpatient clinic visit. Surrounded by family members, she struggled at first to answer my question about what cancer is and said, “[i]t’s a really... it’s hard to explain...” With hesitation, she slowly described how cancer is “[s]omething... that... makes you special...” I asked her how, and she proceeded to explain “cause...I don’t know. Cause, you get to meet a lot of people with that and not a lot of people are able to do that.” While Jacob praised the cancer that no longer inhabited his body, Tabitha was actively undergoing treatment to eliminate the very cancer cells that make her feel “special.” Other adolescents similarly appreciated the people they had met throughout their

experiences with cancer, but she was the only one to define the disease with such glorification. In her eyes, the abnormal chaos of cancer was an exceptional life experience. By finding something to value within the abnormal, she countered the societal assumption that “the majority of the population must or should somehow be part of the norm” (Davis 6). Tabitha inverted the misfortune of cancer, positively illuminating its atypicality as unique and extraordinary.

Just as cancer means something different to each adolescent, many displayed conflicting understandings and emotions towards their treatments. The same ten-year-old who praised “good treatment” in the epigraph of this chapter also wrote:

Handwritten text in pink ink that reads "Medicine STINKS!". The word "Medicine" is written in a cursive, lowercase style, while "STINKS!" is written in a bold, uppercase, blocky style. There are small dots at the end of the words.

Together, these paradoxical statements reveal his mixed emotions towards treatment. Although he likes how it rids the body of cancer cells, he regards “medicine” itself as unfortunate and unpleasant. He recognizes the necessity of treatment, albeit it may be an unfavorable experience.

Despite the many antagonistic attitudes towards chemotherapy, some adolescents seemed more aware of its ultimate purpose to treat cancer. I have to admit—I was discontented that more adolescents did not look beyond the detrimental effects of chemotherapy and appreciate its aim to eradicate cancer. At the same time, I think it is important for me to pause and recognize how my disappointment reifies the power dynamic inherent in my methods. For me to experience any sort of dissatisfaction with how adolescents understand treatment is unduly elitist; it is not my place to criticize how adolescents make sense of chemotherapy because doing so threatens their agency. Instead, my concern lies in broader systemic insufficiencies: are there better ways to

help adolescents cope with treatment by emphasizing its long-term benefits? It seems fundamental to me that adolescents realize and remember the end goal to treat cancer, despite the pain and suffering of treatment in the present. Enhancing conceptualizations of cancer and chemotherapy could, I believe, ease the coping process and enable adolescents to have more input and control over their medical treatment.

In fact, some adolescents did favorably empower treatment as a force over cancer. One said she liked how chemotherapy will “destroy cancer” while another appreciated that “[t]he cancer gets stopped.” Treatment acts as a potent agent to trigger the cessation of cancerous growth, with cancer as an evil to be put to an end. Regarding treatment as a weapon against cancer allows adolescents to relinquish control over the progression of disease. Instead of accepting that the disease depends entirely on attitude, treatment intervenes and creates space to separate an adolescent from their cancer, thus relieving their burden of responsibility for the disease. Some adolescents valued the good intentions behind chemotherapy’s destructive effects on cancer, and this appreciation can help them come to terms with the feelings of helplessness often associated with living with disease.

In describing his treatment with gratitude, one adolescent in remission referred back to his definition of cancer as “something you can die from.” He started to say, “if it weren’t for the treatment, I would’ve been...” His voice trailed off as he swiped a finger across his neck and made a *krrr* sound. “It’s true,” he concluded, nodding. As someone no longer undergoing treatment, he had a fresh and grateful perspective of chemotherapy. He seemed to genuinely esteem its purpose because he realized that his life was once at stake. His gesture represented death through a symbolic beheading; by alluding to this method of dying, this adolescent brought out connotations of cancer as violent but also as punishing. This “punitive” aspect of cancer, just

as Susan Sontag cautions against, transforms treatment into an act of justice that heals an ailing adolescent. In this moment, he chose to express himself outside of words. He was comfortable defining cancer explicitly in relation to “death” before, so why did his words falter now? Here, he seemed unable to say the word “dead,” perhaps because he was acknowledging his own proximity to death rather than more abstractly defining cancer. His actions remind us of the limits of expression through language, for “the experience of illness and dying lies beyond our ability to describe it fully in language or to impart to it coherence or expressive form” (Conway 16). By communicating beyond words, this adolescent expressed the seriousness of illness. Treatment takes on a heightened level of importance, for it prevented the unfathomable possibility of his death. Just as with cancer, treatment is not bound as an evil or a force of good.

As I have illustrated throughout this chapter, the cancer narratives gathered in this research demonstrate the diverse array of adolescent perspectives that arise from different stages in treatment. The shared elements of these adolescent views as well as the ways that these understandings may differ can provide insight into how adolescents begin to create a self with cancer. Adolescent points of view often troubled the binary of good and evil used to conceptualize illness, sometimes conceiving cancer and chemotherapy outside of these boundaries by appreciating their disease or despising its treatment. Since cancer and chemotherapy are generally integral to adolescent experiences, recognizing the slippage between these, the similarities and the misunderstandings about them, can help illuminate how adolescents understand and make sense of their diagnosis and treatment beyond the labels of “cancer” and “chemotherapy.” With these definitions in mind, the following chapter will delve deeper into the ways that cancer and chemotherapy shape an adolescent’s creation of a self.

Chapter Three

“Cancer at a Crappy Age”: Creating an Adolescent Self with Cancer

“That’s what sometimes makes me mad or upset is that I got it, I got cancer at a crappy age...this is not the age.”

—Andy, fifteen-year-old male

Since cancer is a life-threatening disease, cancer in adolescence is particularly jarring. Andy was upset about having cancer as an adolescent, when he was “supposed to be having a great time and everything.” This intersection of adolescence and illness qualifies this population as “vulnerable in two dimensions,” as I explained in chapter one (Couser, *Vulnerable Subjects* x). With cognitive development and the physical changes associated with puberty, adolescents exist in a state of liminality, suspended between childhood and adulthood. In the preceding chapter, I explored how adolescents conceptualize and contest understandings of cancer as a loss of control, as impairment and disability, and as a blessing and a curse. But, conversely, how do these perceptions of cancer shape how adolescents understand themselves with the disease? In this chapter, I turn my attention to how cancer affects an adolescent’s emerging sense of self.

The concept of the self in autobiographical or self-narrated works such as these adolescent narratives is complex, largely because it has been defined and explored from many different disciplinary perspectives. Social science fields such as psychology,²⁴ sociology,²⁵ and anthropology are each drawn to the cognitive, social, and cultural influences on the creation of a self, respectively.²⁶ Disability studies and medical humanities examine the relationship between the body and the self,²⁷ while narrative medicine observes how narrative complicates this

²⁴ See Jerome Bruner, *Making Stories: Law, Literature, Life*.

²⁵ See Arthur Frank, *The Wounded Storyteller*.

²⁶ See Georges Gusdorf, *Conditions and Limits of Autobiography*.

²⁷ See Dene Granger, *A Tribute to My Dyslexic Body, As I Travel in the Form of a Ghost*.

embodied self.²⁸ Nevertheless, these many conceptions of the self overlap and interact with one another. With these scholarly perspectives in mind, I consider the self primarily by examining the various ways an adolescent self is created and sometimes challenged in narrative expression.

My method for defining the self leans heavily on life writing scholar Paul John Eakin's definition of the self. Based on psychologist Ulric Neisser's categorization of a conceptual self, Eakin defines identity as "the version of ourselves that we display not only to others but also to ourselves whenever we have occasion to reflect on or otherwise engage in self-characterization" (*Living Autobiographically* xiv). Identity regards the perceived self, at least insofar as it appears to us and to others, and bridges these perceptions as one through the "interaction of a person's self-conception with how others conceive her" (Nelson 6). The participants in my research can identify as adolescents and as patients, but beyond these identities, the self is encompassing of all experiences, emotions, and interrelations with the surrounding world. Although the phrase "the self" may be deceptive, Eakin clarifies, "there are many stories of self to tell, and more than one self to tell them" (*How Our Lives Become Stories* xi). Adolescents share different selves through recollections about diagnosis, tense anxiety about blood draws, or conversations in hospital corridors. The composite adolescent self that incorporates these many selves can also transcend identification with cancer, for it is an important but not totalizing aspect of the self. This understanding of the self explains why Eakin "prefer[s] to think of 'self' less as an entity and more as a kind of awareness in process": the creation of identity is ongoing. Identity can change with each moment in time, and temporality grants the self in its entirety the flexibility to evolve (*How Our Lives Become Stories* x).

²⁸ See Rita Charon, *Narrative Medicine: Honoring the Stories of Illness*.

As Eakin puts it, the self, then, is “the larger, more comprehensive term for the totality of our subjective experience”: I explore this composite self to gain insight into the subjective experiences of adolescents with cancer (*Living Autobiographically* xiv). Understanding selfhood as multifaceted and fragmented has encouraged me to focus on the different selves or dimensions to this composite self. I use the term “the self” to refer to the constellation of selves that make up an all-encompassing self. In this chapter, I examine how experiences with cancer may affect facets, or constituent selves, of a composite self that adolescents construct through narrative.

With this definition of an overall self, we can observe how constituent selves are created and challenged over time through the self-narrating process. Just as social and cultural factors contribute to self-fashioning, “narrative can be said to play a privileged role in the process of self-construction” (Miller et al. 292). Eakin takes this notion one step further by claiming that narrative and self are integral to our identities as individuals, for “narrative is not merely *about* self, but is rather in some profound way a constituent *of* self” (*Living Autobiographically* 2; emphasis in original). Narrative not only informs the self-creation process but is itself a process of self-making. Inevitably, we create a self in creating narrative. Other scholars have even conceptualized narrative based on this relation to the self, defining narrative as “an active lived process inseparable from self when autobiographical elements are involved” (Kelly and Dickenson 254). If narrative and self are so intertwined, especially in autobiographical works where the focus of narrative is largely the self, then what are we to do with the “autobiographical gap,” the space “between the person doing the writing and the person doing the living” (Charon, *Honoring Stories of Illness* 70)?

To account for this autobiographical gap, a space central to my research, my method bears witness to both the person creating the narrative and the person represented within it. I

believe that considering the constituent selves involved in narrative creation alongside one another provides greater insight into an adolescent's composite self. In life writing, autobiography scholars Sidonie Smith and Julia Watson identify a total of four narrated first person singular "*I*"s that are noteworthy. My interactive approach involves two of these narrative expressions of the self: the "person doing the writing" becomes "the narrating 'I'" (the authoring individual) and the "person doing the living" is "the 'real' or historical 'I'" (the individual whose life is concerned) (Smith and Watson, 2nd ed. 59). The *real* "*I*" may be unavailable except through already produced narrative (for literary scholars are not often involved in an author's composition process), but my research has enabled me to interact with the adolescents who created these narratives. Since both expressions are constituent components of the self, this interactivity can inform our understanding of the adolescent self as created through narrative.

While I observe the component of the self found in the *real* "*I*" in this chapter, I focus on the *narrating* "*I*," "the narrated 'I' (the identity this person takes on as a subject of their autobiography) and "the ideological 'I'" (the person as socially and culturally constructed in relation to others) (Smith and Watson, 2nd ed. 72-3). Given that narrative creation is a self-making process, I analyze the selves relayed through narrative, the narrating self that tells of them, and the ideology infused within these representations to understand the composite adolescent self. These narrative selves, whom I will clarify using these singular "*I*" terms, provide a more holistic understanding of how a composite adolescent self is constructed through narrative. I posit that these multiple narrated forms each share different adolescent selves, thus illuminating the many dimensions, or constituents, of an all-encompassing adolescent self.

What happens, then, to this self upon the diagnosis of disease? Sociologist Arthur Frank recognizes how disease and its broader counterpart of illness are instantaneous but also enduring:²⁹ “[d]isease interrupts a life, and illness then means living with perpetual interruption” (*The Wounded Storyteller* 56). With this alteration occurring both immediately and lastingly, “[i]llness intensifies the routine drives to recognize the self” (Charon, *Honoring Stories of Illness* 87). Illness challenges an individual’s identity and even life, inciting one to reconcile these conflicting identities to become a new self with disease: “the self never just *is*, especially during illness or trauma” (Frank, *Necessity and Dangers of Illness Narratives* 165). What does this drive to create a self signify for adolescents, who are often characterized by an especially fluctuating self? Adolescents, with changing bodies and developing minds, create a sense of self with illness by claiming cancer as part of their identity while disengaging themselves from their disease.

The experiences adolescents have with cancer and the selves they create vary. I do not claim to make broad generalizations about the identities of all adolescents with cancer. Instead, I consider recurring themes and isolated incidents, based on the selves that bear resemblance to one another and others that differ. In this chapter, I explore prominent narrative tensions that these adolescents expressed, which fall under several categories: conflicts of coming-of-age, somatic experiences with cancer, concession to medical demands, desires to retain normalcy, and the self as a social being with cancer. By analyzing facets of the self that adolescents reveal, I argue that the process and product of life writing demonstrate the subjective complexity of living with cancer. The following sections explore the many selves that constitute an all-inclusive adolescent self with cancer, with different facets that do indeed overlap and intertwine.

²⁹ As I mentioned in the introduction, I use Arthur Kleinman’s distinction to define disease as pathological and illness as the “innately human experience of symptoms and suffering” (1).

“I am, like, having to grow up”: Encountering illness in adolescence

Perhaps one of the reasons a cancer diagnosis in adolescence can be especially distressing is because cancer complicates the coming-of-age process. As clinical researchers have noted, “[a]dolescents are beginning to strive for autonomy and independent decision-making – a diagnosis of cancer makes them dependent again and not in control of their lives” (Albritton & Bleyer 2003). By thrusting an adolescent into the biomedical realm, a cancer diagnosis immediately diminishes one’s sense of agency. Yet simultaneously, these experiences can catalyze adolescent maturation. These somewhat conflicting forces challenge an adolescent’s emerging sense of self at an especially vulnerable time, for they are “developmentally focused on identity formation” (Jones, Parker-Ralay, and Barczyk 1037). I did not expect adolescents to explicitly address this struggle, for it seemed like they would consider this tension inevitable, yet several expressed frustration about getting cancer as adolescents.

The occurrence of illness can pull an adolescent towards the innocence of childhood and maturity of adulthood; how adolescents respond to these ideological forces points to different ways that adolescents may create a self with cancer. As she waited for her doctor to arrive, Tabitha, a thirteen-year-old, lamented how cancer truncated her childhood and she “wasn’t able to be like a kid...I had to be like not able to do like kid stuff.” Although she was still undergoing treatment for her cancer, her *narrating “I”* uses the past tense and indicates that a break with childhood had already occurred, perhaps alongside her diagnosis. With an emphasis on this negative effect of cancer, her narrated self seemed unable to move beyond this loss and burdened by a premature push to grow up. But what prevents this adolescent from doing “kid stuff”? Is it the physical debilitation imposed by cancer or treatment, or rather society’s ideological expectations that she will face her illness bravely and maturely? Regardless of which she may be

referring to, growing up is daunting to her. Fifteen-year-old Jacob, on the other hand, was frustrated for the opposite reasons. He complained about being incessantly attended to as though he were a child. When I asked him what he wanted the adults in his life to know, Jacob said emphatically, “[d]on’t baby you...I just...I don’t want that.” He did not want to be pampered because of his diagnosis and, impassioned by his adolescent desire for autonomy, his *narrated* “I” opposes to being infantilized. With contrasting perspectives, Tabitha and Jacob draw attention to varying adolescent preferences. These adolescents respond differently to the ideological pressures imposed by a diagnosis, particularly to cope maturely but also to stay young. In the presence of illness, it becomes even more ambiguous where adolescents lie in the liminal space between childhood and adulthood. Beyond these preferences, however, Tabitha and Jacob also seem to invoke (and condemn) sociocultural responses to illness; behavior towards the ill may ignore how adolescents themselves want to be treated.

Individuals surrounding adolescents with cancer do not solely determine how adolescents experience growing up with illness, though, for cancer itself takes a toll on one’s mind and body. Caught between conflicting forces to grow up and preserve youth, ten-year-old Xander explained how “I grew up faster as in not my body, but...I grew up faster as I learned a lot more a lot quicker.” While cancer may not have accelerated his physical development through puberty, his narrating self was aware that cancer affected his mental maturity. What does this difference in development mean for his sense of an adolescent self? Cancer catalyzes a disjunction between his physicality and his transformed mentality that disjoins his self. The *narrated* “I” and the self are both bisected, causing increased pressures that can exacerbate adolescent challenges. Illness, then, complicates the already present conflicts in the coming-of-age process. The unpredictability of how this change may affect an adolescent, however, emphasizes the need to

follow an adolescent's lead and be receptive to how an individual wants to be treated. Xander's observation also points to the broader inadequacy of clinical approaches towards illness and youth, for it is possible that these encounters do not grant the space necessary for adolescents to appropriately express and cope with these concurrent life changes.

This intersection of cancer and youth was of particular concern to a sixteen-year-old inpatient. She explained how cancer "made me more like responsible and more...umm grown up about it ... I am like having to grow up to take care of myself and to be responsible, like taking my pills and everything. And other teens, they don't really have to go through that." In this case, cancer accelerated development and coerced maturation, forcing responsibilities onto this adolescent for which she would otherwise not be accountable. This transformation also seems to have influenced her advice. When asked about what she would tell others with cancer, she was the only adolescent to inquire about age. Her *narrating "I"* proceeded to advise accordingly, first addressing a child less than ten years of age: "I think I would say that they're gonna be ok and that, just keep positive, just keep them positive and motivated about getting better...I think I would tell a teen that it's ok to be scared, and not know what's going on." By tailoring her advice, her narrating self recognizes that the experiences and challenges faced by children and adolescents with cancer are not the same. Her juxtaposition of these age groups inadvertently emphasizes her belief that adolescents, in comparison to children, are more capable of handling fear. She validates these emotions in an attempt to push back and liberate adolescents from the infantilization and maturation often imposed on those with illness. She comforts her peers by resisting stereotypes of bravery and expectations that "they will be 'fighters,' that they will 'beat this thing'" (Segal, *Cancer Experience and Its Narration* 301).

When I asked her why she would provide different advice to children and to adolescents, she speculated that age would influence one's understanding of cancer. If that is the case, then what does she imply about how cancer may affect an adolescent self? Her *ideological "I"* insisted that simple, encouraging advice is more suitable for younger children, for they would be less likely to understand cancer. "[K]ids that do understand," other adolescents like herself, "might be more tensed up or not like open up about how they're feeling." Her narrated self understood the hesitance, the anxiety, even the isolation that other adolescents with cancer might feel. In comparison to children, adolescents have a heightened understanding of cancer that can be helpful yet additionally challenging for them, and she felt as though their experiences necessitated validation. Teenagers, she claimed, want their emotions, both the fears and joys, to be acknowledged. She portrayed the adolescent self as particularly vulnerable to emotional struggles and in greater need of external affirmation. Her *narrating "I"* seemed to allude to her own coping process and personal experiences with undervalued emotions. Instead of reiterating optimistic notions of the future, she sought to comfort others by recognizing struggles of the present. It is almost as though she provided advice that she wished she herself had heard. By alluding to responses of optimism and emotional validation, her *narrated "I"* revealed some of the conflicting expectations about how adolescents with cancer should behave. For adolescents who are particularly vulnerable due to their age, these diverging sociocultural reactions to illness can be especially confusing for one's *ideological "I"* and sense of self overall. Cancer's intervention into the complex coming-of-age process thus has both subtle and blatant consequences. Illness impacts the unmaking of a child self and the making of an adult self, a simultaneous (de)construction process that is never neat, especially with cancer.

“I don’t feel like it’s my body anymore”: How cancer alienates the somatic self

Before cancer permeates into other aspects of one’s life as an illness, it undoubtedly affects an adolescent’s body, or somatic self, as a biological disease. How do these physical effects in turn influence an adolescent’s creation of a self? This question poses a relatively new concern to narrative studies, for “[t]hrough our selves and our lives are fundamentally bodily, the body has not, until recently, figured very prominently in life writing” (Brownley 165). While the mind and body were once considered separate entities, many scholars have now turned their attention to the connection of the mind and body to recognize “the human condition as both flesh and spirit” (Couser, *Autopathography* 163).³⁰ Even beyond this link, scholars have contemplated how the mind and body relate to the self in its entirety. Eakin poses an important question about this relationship: “[a]re bodies and selves something we ‘have’ or something we ‘are’?” (*How Our Lives Become Stories* 29). In essence, are bodies and selves objects to be possessed or ways of existing? According to physician and narratologist Rita Charon, this question is not to be framed as an either/or situation. Instead, both possibilities deserve merit because “[t]he self has—and is—a body” (*Honoring Stories of Illness* 76). Along this line of reasoning, the body has and is a self as well, for they are intertwined as both an object and a way of being. But what happens to the self when this body goes astray and is taken over by cancer cells?

Since “bodily dysfunction tends to heighten consciousness of self and of contingency,” adolescents who explicitly referenced their bodies in their narratives described how cancer dissociated these components of the self, leaving their overall sense of a self in despair (Couser,

³⁰ Philosopher René Descartes proposed the influential idea of mind/body dualism, but scholars have ardently worked to move away from this notion. See Nancy Schuper-Hughes and Margaret M. Locke, *The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology* and Marcel Mauss, *Techniques of the Body*.

Recovering Bodies 5). These adolescents were distressed by immobilization, physical impairment, even estrangement from their bodies through diagnosis and treatment, all of which seemed to restrict one's sense of self. Those diagnosed may become aware of the "physical changes that had occurred that signaled a passage from being healthy to being ill," (Carlick and Biley 310). Even though cancer fundamentally challenges physiological functioning, most adolescents seemed more troubled by how the disease affects their lives as an illness. Consequently, not many addressed this embodied experience of cancer. Part of this aversion to narrating the physical effects of cancer may be attributed to the nature of corporeal life writing: since "the experience of embodiment becomes transformed, changed, and is (re-)created in narrative," it is inevitable that "the bodily experience described in the text will always be different from the 'real' experience and even more so if this embodied self is sick" (Gygax 296).

As I sat beside one inpatient, I asked her what she did not like about being in the hospital. This sixteen-year-old's response seemed to expand beyond the scope that my question had intended, as her *narrating "I"* took into consideration not only her experiences in the hospital but also with cancer: "I guess, just being stuck... having tubes going through you and everything, being like...well, not necessarily like being stuck in your room, but just like being sick and like not feeling well and not being able to go get out of the room and doing stuff." Her narrated self grappled with feelings of "being stuck" both literally and figuratively. Physically, the tubes that run in and out of her body entrap her movement. These foreign objects imprison her somatic self as she is forced to sacrifice her mobility. She also alluded to how treatment's side effects can suppress the immune system, causing an immunocompromised state that requires patients to stay isolated in hospital rooms, confined without a choice. At the same time, her *narrated "I"* experienced feelings of suspension as more than physical sensation. Disease progression or

treatment complications suspend adolescents in an unwell state and lead to hospital admission. This helpless experience of disease parallels and is even embodied by the vulnerability of her somatic self. She undergoes an analogous loss of agency through her physical body and, as I explore later in this chapter, her patient identity.

On a broader level, most adolescents strongly disliked how cancer and treatment physically stripped them of capacities integral to their selfhood. A ten-year-old male is honest and straightforward about these limitations:

• Can't do a lot of things

From dribbling basketballs or kicking soccer balls, to going to school or spending time with friends, adolescents often introduced themselves to me by the activities they do. Lexie likes to write stories, Andy works as an umpire, and Xander takes care of a pet ferret. “When I got cancer, I had to quit all of this,” one adolescent told me somberly. What happens to the self when cancer limits physical abilities and adolescents cannot do what they enjoy? Many feel robbed of their strengths and, by virtue, the very passions they most cherish. These are often the passions that helped them to define a self before cancer. Adolescents expressed having no choice: cancer threatens normal physical abilities and forces them to forfeit their lifestyles for treatment. In a sense, the body becomes foreign to adolescents as they lose these strengths. By hindering basic functions, cancer tends to further strip an adolescent’s self of agency over one’s body.

In addition to these functional limitations, seventeen-year-old Celeste also disliked how treatment, which she described as “all the stuff going into my body,” entered and intervened into her somatic self on a more intimate level. She elaborated, saying, “I don’t feel like it’s my body anymore.” With so much else co-inhabiting her body, her *narrated “I”* no longer felt

comfortable identifying it as her own. Celeste spoke as though she was unauthorized to claim her body: her self no longer has and is her entire body. Upon this invasion of treatment, what happens to the adolescent self? By inserting harsh chemicals, chemotherapy transforms Celeste's body into a cyborg of sorts, a "hybrid of machine and organism" as the medical institution runs through her veins (Haraway 83). These foreign compounds enter the body, and since the body is more than a vessel but also a crucial component of the self, this dissociation has disastrous effects on an adolescent's sense of self. Celeste's *narrated "I"* lost a part of her self. Her body becomes estranged, her self left helpless. Upon the corruption and eventual loss of physicality, Celeste's self entered a state of despair as she was stripped of agency to own her body.

Even though cancer has physically affected these adolescents to different extremes, the loss of control over their bodies can leave them especially vulnerable. Cancer challenges the self's possession of a body, taking the somatic self under its own control. In doing so, cancer estranges the body from the self to which it once belonged, leaving an adolescent somewhat disembodied and consequently disempowered.

"Let the doctors do what they have to do": Embracing passivity as a patient

The emergence of cancer in the body also deems an individual subject to medical care, which inevitably "involves relinquishing control over one's body, and one's story" (Couser, *Recovering Bodies* 10). If "one's story" is the life lived by one's self, then the self becomes powerless to the medical institution. Not only does medicine subjugate the body but also the self in its entirety, for "[a] patient is understood to belong to a doctor or other health care professional, or more generally to an institution" (Linton 234). While cancer demands that these

adolescents forfeit control over their bodies, medicine calls for them to surrender the totality of their self.

Adolescents respond to being immersed in the medical realm in various ways, some more positively than others. The lack of agency inherent in clinical experience is a defining component of patient identity. Passivity is not only expected but even demanded, for patienthood requires unquestioning submission to medical authority. Smith and Watson explore how these clinical environments enforce patient compliance:

[T]hrough the “discourse” of medical institutions (the language, images, metaphors, and narratives through which medical institutions produce and circulate knowledge about persons) people learn to understand themselves – “experience” themselves – as “patients” in need of healing or as “diseased” or “insufficient” bodies in need of surgical intervention and repair. (2nd ed. 32)

Patients acquire a new sense of inadequacy as the flaws in their body become imperfections of the self. With limited autonomy due to their young age, adolescents lose additional agency as patients. If the “[s]elf is a concept one of whose defining properties is agency,” how does this loss impact an adolescent self (Bruner 41)? Medical expectations of patient compliance can present a challenge that undermines adolescents with cancer who are striving for autonomy.

Several adolescents reflected on their personal experiences as patients and shared advice for others adopting this role. While some were not hesitant to yield to medical procedures, others objected to these expectations. Fifteen-year-old Andy claimed, “I don’t mind any [procedures]. I’m here for whenever they need to do it.” His narrating self willingly accepted his role as a patient and trusted that there is a “need” at the root of all medical directives. Andy embraced passivity and insisted, “[i]f they need to do it, then I’ll do it”; when his narrating self changed the

subject of the sentence from “they” to “I,” his *narrated “I”* accepted this patient role with purpose and deliberation. Andy exerted his own agency by consciously deciding to be a compliant patient in order to assist medical professionals in treating his cancer.

By encouraging adolescents to submit to the medical practice, Andy reinforced an ideological “objectification of the body as the site of technical intervention, and as the material or even property regarding which autonomous persons exercise free consent” (Cahill 200). His *ideological “I”* urged others to “[j]ust...go with the flow,” advocating for patient malleability in the hands of medicine. At the same time, thirteen-year-old Mary was frustrated with this objectification when her *narrating “I”* complained, “I do not like them practicing on me.” Because of her age, she likely did not have a say in whether she wanted training health professionals to be “practicing” on her or not. In these moments, when a nurse may search endlessly for a vein or a physician may struggle to aspirate bone marrow, adolescents can feel especially victimized. For the most part, however, these adolescents willingly concede to the medical institution, though they may sometimes be uncomfortable with the demanded passivity.

In clinical encounters, adolescents had different ideas of how to best exert their agency as patients. Fifteen-year-old Lexie, who was diagnosed at the age of two and has had multiple relapses ever since, urges others to voice their concerns:

Another piece of advice is to speak up. If you don't like something or something doesn't feel right you need to say something. It is so important for you to voice your opinion

Lexie's *narrating “I”* advocates for patients to take charge of their disease and “speak up,” to enact agency through language. Lexie proposes that instead of withholding opinions, communication can be empowering for adolescents with cancer. But what challenges arise when

patient language can be “unvalued and unrecognized in medical culture” (Jurecic 48)? A sixteen-year-old was troubled by the difficulties encountered when communicating within the clinical sphere: “I guess it’s like harder for us to tell them [adults] like what’s wrong and stuff because we really don’t know what’s wrong.” She wanted adults to know that expression and communication are intrinsic challenges to being an adolescent with cancer. This adolescent suggested, “we really have to like, make a conclusion together. Like, like the adult and the teen to figure out what’s wrong.” She attributed this obstacle in expression to a lack of basic understanding of what is happening to her body as well as an uncertainty of how to share these intimate experiences with others. As a patient, she advocated for concordance, a notion that replaces expectations of medical compliance with the more balanced “expertise of patients and health professionals [that] can be pooled to arrive at mutually agreed goals” (Bissell, May, and Noyce 851). In this shared knowledge of suffering, collaboration rather than mere domination and subordination can arise between doctor and patient, adult and adolescent. Despite providing different suggestions, both adolescents problematize the idea of medical compliance in favor of concordance. There are ways, it seems, to be a good, actively engaged patient.

Based on personal experiences with clinical care, these adolescents had different opinions of health professionals, which affects how the self copes with healthcare. Andy, an inpatient undergoing treatment, was firm in his belief that “[w]hatever they tell you you need to do.” He urged others to “just go ahead and do it cause they’re right and it’s working.” With steadfast faith in health practitioners, Andy’s narrating self left no room for wrong decisions or failed attempts. Zack, a sixteen-year-old in remission, voiced similar sentiments of belief that “[t]hey know what they’re doing,” but he also recognized that “they’re going to help *as best as they can*” (emphasis mine). Zack was confident in the knowledge and the goals of health

practitioners, but he also seemed to be aware, consciously or subconsciously, that there may be limitations to this potency. With multiple relapses, Lexie seems less sure of medical success:

doctors and nurses can sometimes fix things to make them more comfortable, and remember they are human too they could have made a mistake.

By remembering and reminding her reader that doctors and nurses “are human too,” her narrating self challenges the inherent power dynamics in medicine that render clinicians as entitled over patients. Lexie invokes this common thread of humanity to bridge the gap between health providers and recipients. Her sharp perception of medical paradigms—for she recognizes the immense and sometimes unreasonable expectations placed upon clinicians—demonstrates her keen understanding of the medical sphere. Lexie knowingly accounts for the successes but also the failures in medicine, both of which she has experienced as a relapsed patient.

But if medical authority tends to be established at the expense of adolescent agency, then how do the limitations of medical intervention undermine its authority and imperil these patients? In particular, what happens to an adolescent self when medical practitioners cannot fix things or have made a mistake? These implicit yet important questions acknowledge how the realization of medicine’s insufficiencies can be discouraging for adolescents, to say the least. It is not easy to forfeit agency to the medical practice; it can be even more difficult to do so upon realizing the potential futility of it all. As such, it makes sense that some adolescents would prefer an optimistic perception of medicine to one consumed by its imperfections. Since the “mind may be seen as being potentially able to influence the body (as in the common motif of a ‘fight’ against cancer),” the disheartening awareness of medicine’s limitations even has the potential to damage the somatic self (Kelly and Dickinson 272). Despite the tension to be a passive, compliant patient while maintaining a self with agency, adolescents find modes of

empowerment such as positivity, even within the firm grip of medicine. These adolescent perspectives illuminate some of the ways that expectations of medical compliance may undermine the agency of this already vulnerable population.

“I just try to be a normal teenager”: Striving for normalcy amidst cancer

The desire for normalcy, to fit in amongst peers, is often considered characteristic of adolescents, for this population is also known for being “developmentally focused on...peer relationships” (Jones, Parker-Ralay, and Barczyk 1037). For those with cancer, this urge can be exacerbated by the increased threat disease poses to normalcy. Arthur Frank describes how “[t]o live in deep illness is to be constantly acutely aware of one’s differences, less from those who are differently ill and more from those who are not ill” (*Illness and Autobiographical Work* 152). Many adolescents grappled with what it means to be normal, a few claiming normalcy while others felt different because of their cancer diagnosis and treatments. Varying ideas of what “normal” is can place additional pressure on adolescents and strain one’s sense of self.

Only one adolescent blatantly denied feeling different because of cancer. As a sixteen-year-old in remission, Zack claimed, “I would consider myself pretty normal.” While this may be in large part because his *real* “I” was no longer undergoing treatment and only coming to the hospital for yearly check-ups, his *narrating* “I” recalled having a similar attitude at the time of his diagnosis: “I felt pretty normal until I had the surgery. I mean, everything was...I felt the same, it was just that I was peeing blood, that was why I didn’t...that’s how they found out, I mean, other than that I was completely normal.” It was neither the cancer diagnosis nor physical symptoms but rather the surgery that changed Zack’s feelings of normalcy. Interestingly, although he admitted something changed due to his surgery, his narrating self refrained from

talking about how surgery changed him. Instead, his *ideological* “I” reinstated steady feelings of normalcy. He did not aspire to be normal because he never felt that cancer changed him.

Lexie expresses similar feelings of normalcy, as a fifteen-year-old in her fifth relapse:

Unfortunately, I have been diagnosed 5 times so for me, after a while, the words “you have cancer” didn’t really faze me.

Her narrating self defines each relapse as a diagnosis and seems resilient to these recurring interruptions of illness, even though new cancer cell detections were unforeseen but not unprecedented. While future relapses cannot be predicted, treatment itself is not foolproof and the possible recurrence of cancer remains. I use the word interruption to indicate a change or break, but despite its negative connotations, adolescents experiencing interruption due to cancer may not necessarily consider it bad. Lexie’s use of the word “diagnosis” interchangeably with relapse suggests that these relapses are more than mere re-presentations of a past cancer but are rather distinctively new like a diagnosis. With multiple relapses and much time spent in clinical environments that are saturated with medical language, it seemed to me as though her use of the word “diagnosis” was purposeful, especially given that this synonymous use with relapse did not occur verbally. Even though her word choice may be interpreted in many ways, it seems like she regards each relapse as a separate event, each bout of cancer separated by intermittent periods between “diagnoses.” Something is different about each recurrence of cancer to Lexie, even though her *narrated* “I” claims each relapse did not affect her.

With so many years of her life spent in treatment, the abnormal disease of cancer has become somewhat “normal” for Lexie, or at least as normal as a life-threatening disease can be for an adolescent. She told me, “since I’ve been at it for so long... it’s kind of my life.” Lexie

advocates for newly diagnosed teens to normalize their illnesses just as she has:

A.) My advice to any teen that has just been diagnosed is to live life like nothing is going on.

She advises others to hide the differences imposed by a diagnostic label, to conceal emotional struggles and instead imagine and enact a life as though cancer were not a part of it. How might encouragement to be, or at least attempt to be, normal in effect devalue abnormal experiences of adolescents with cancer? These words of advice seem as though they would be effective for some and detrimental to others. When asked about what he liked or did not like about treatments, Andy discussed his own attempt at normalcy: “I don’t think about it [cancer] really, I just try to be a normal teenager. Going to movies, hanging out with girls and guys, all of that I don’t think about it. I just try to go back to be normal, whatever comes up comes up and we’ll deal with it.” For others, however, the need to feign normalcy might actually undermine experiences with cancer. Thus, “...the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person (Davis 3). These adolescent perspectives point to how the very notion of normalcy, the ideal of a desirable norm, is structurally problematic: it undervalues and ignores the diversity inherent in human nature.

To illustrate how he personally maintained normalcy despite cancer, Andy told me, “[y]eah, this is kind of out of it, but even though I still have all the cancer and stuff, I still have a job. I do 2 jobs. Mark fields and umpire.” Andy broke away from the narrative topic of his cancer for a brief side note; while he acknowledged that this information may be tangential, an underlying motive urged him to tell of the self that exists outside of cancer. Andy’s response exemplifies how “[i]ndividuals may project the noncancerous self through narrative for various reasons, in particular appearing ‘normal’ to audiences” (O’Hair, Scannell, and Thompson 422).

With this interjection, Andy's *narrated "I"* attested to the "normalcy" of his life. Despite his cancer, he has maintained a routine as mundane as having a job. Normalcy is set up in opposition to cancer, for "even though" this disease has interrupted his life, he has retained aspects of his life before diagnosis. Additionally, this admittance of normalcy emphasizes how "patients can use narratives about their noncancerous persona to reinforce in themselves an identity that cancer is only a part of who they are, not what they are" (O'Hair, Scannell, and Thompson 422).

Normalcy, as conveyed through these narratives, is a way of accepting cancer without being entirely defined by it. Despite the interruption of cancer in these adolescent lives, many find ways to retain normalcy, or at least appear as such, amidst an abnormal experience.

"It changes your relationships with people": Shaping the social self with cancer

Cancer's effects on an adolescent's ability to be "normal" more broadly influence their relationships with others. One adolescent mentioned these social consequences when he began to describe how cancer changed his life. "[W]hen I went in the hospital," Xander explained, "I had lost most of my social identity." While it may be ambiguous how his narrating self defined his social identity, he proceeded to clarify that it was only "some" of his social identity that was lost: "relationships changed...it changes your life, I mean, you're a different person." The hospital isolates Xander and diminishes his social identity. At the same time, cancer itself catalyzes a series of changes in an adolescent's self that affect one's social being. Some adolescents appreciated how "[y]ou get stronger relationships with the people who you don't have such great relationships with." Cancer intervenes into their social lives to bring them closer to others, which "wouldn't have happened any other way if this hadn't... cancer hadn't happened." Illness presents an occasion for social transformation, for better but also for worse.

What struck me was that the behavior of loved ones was yet another source of misery for some adolescents. Several felt guilty about the strain cancer imposed on these relationships. They struggled to reconcile their own emotions with the feelings of those around them. Celeste was overwhelmed: “I felt like a burden to my family, like why am I putting them through this. Like, I wasn’t really worried about myself, I was worried about like my family.” Social relationships took on a heightened level of importance as she watched cancer change not only her life but also the lives of those she cares about. Her *narrated “I”* took responsibility for the emotional toll and the logistical challenges that cancer poses to her family. This feeling of being burdensome to others is a common disability trope that forces an individual to face emotions of guilt regarding their condition. Celeste felt at fault for the inexplicable disease of cancer and the disruption that it caused. Instead of focusing on her own coping process, Celeste seemed especially concerned by how those around her had been affected by her diagnosis

In addition to feeling guilty about how cancer burdens loved ones, Zack felt helpless and unable to comfort those around him. His narrated self presented “everybody” in opposition to himself, revealing the distinctly different perspectives that arose in the face of cancer. Zack said that he did not like how “everybody was feeling so bad for me, I felt, I mean I felt like I was going to be fine.” He observed an increasing distance that separated and isolated him from his loved ones. Zack perceived the discrepancy between his own outlook and the perspective of others; since “society influences and shapes the bodily experience of the self,” the emotions of those around him personally affect his own experience of cancer (Cahill 401). He struggled to maintain the strength of his relationships amidst these differing views and the distance that they create. I asked him if there was a way that he would have preferred for people to respond, and he elaborated on what was most troubling for him: “it was just like...people crying, it was just

kinda like...it made me feel bad and I couldn't really do anything about it." Upon seeing these emotional expressions of grief, Zack felt that there was nothing he could do to alleviate the pains caused. He was forced to bear witness to the suffering his cancer caused, but he was unable to relieve others of this emotional weight.

The social burdens placed on the self reflect potential misunderstandings of how adolescents cope with cancer, and these reactions can negatively affect adolescents. It becomes crucial that adolescents can voice these concerns, for that is the only way those around them can learn how to alleviate adolescents of additional worry. Adolescents were profoundly affected by how loved ones responded to their situations. These social relationships, both those that are strengthened and strained, thus powerfully impact how adolescents come to cope with cancer.

Throughout this chapter, I have illuminated the diverse effects of cancer on an adolescent self, from its interruption in adolescence to its disruption of social relationships, so as to emphasize the exigency of giving these adolescents the opportunity to have a voice. Only then, I believe, can adolescent experiences with cancer truly be appreciated. The diminished agency experienced by many components of the self increases the vulnerability of these adolescents and contributes to an overall loss of agency for these individuals. Understanding how cancer affects these different facets of the self leads to the following question: what broader impact can this insight and these narrative expressions have? In the next chapter, I will look beyond these facets of the self and explore the implications of these findings on the field of narrative studies and the practice of medicine.

Chapter Four
Multidisciplinary Implications: Narrative as a Process and Product

I dont really know how
 I keep my spirit up. Its
 really hard for me. Most of
 the time I fake a smile
 And act like Im doing
 fine. Mostly because I dont
 want my family or
 friends to worry about
 me.

—Tamia, sixteen-year-old female

In the infusion clinic, with her beeping IV machine audibly inserting itself into our dialogue, Tamia introduced herself as someone who was shy. She seemed a bit reserved during our verbal conversation, but her writing revealed to me how much had been left unspoken. What emerges through various narrative modalities—such as speaking, writing, or drawing—that may otherwise be left untold? By offering these different modes of narrative expression, my interactive research methods create a space for this adolescent to exert her own agency and be honest about her experiences. Tamia wrote this quote after our conversation, admitting to her unexpressed and perhaps unknown (to her and to those around her) tendencies. While this emotional disillusion remained hidden in our verbal conversation, the act of writing may have enabled her thoughts to surface, or at least become legible through written word. Her narrative provides insight into internal distress that may have been imperceptible to those around her.

I believe that this study, which included a number of similarly intimate patient encounters, presents important considerations for life writing research with vulnerable subjects like Tamia. In previous chapters, I outlined my research approaches and delved into several

adolescent cancer narratives. This chapter looks ahead to the broader implications that my approach can have on future research and the many uses for these adolescent cancer narratives. I explore how my process of eliciting these narratives as well as the narratives themselves can contribute to ongoing scholarly discussion in the interdisciplinary fields of medical humanities and narrative medicine and, by extension, narrative studies and medicine.

My approach to gather illness narratives provides a useful framework for optimizing agency in two primary ways: by making space for adolescents to give voice to their experiences and being receptive to nonverbal forms of expression. In the first section of this chapter, I purport that narrative scholars can gain insight by considering the process and product of narration in conjunction with one another. Interactive life writing methods in particular enable agency through nonverbal perception and clinically relevant narrative techniques, such as open-ended questioning. I explore how these research methods can inform the humanist study of narrative and the clinical practice of medicine by providing insight into the creation process and improving nonverbal perception in pediatrics, respectively.

In the second section, I focus on the cancer narratives of these adolescents, a collection of texts that can be studied with other stories of illness, of youth, and of cancer. By examining written, spoken, and drawn narratives alongside one another, I found that multimodality provided alternative avenues for expression that better informed my analysis of these works and of their creators. Multimodal expressions can enhance studies of life writing, and they have the potential to resonate with even broader audiences of humanists. This narrative collection, I believe, can also be an educational tool and a clinically relevant resource for health professionals.

In my introduction, I defended why it is essential for adolescents to have the opportunity to create personal narratives about cancer. Given the importance of providing this narrative

occasion, what exactly are different scholarly audiences to do with these methods and these stories? In this chapter, I argue that equally important to fostering the emergence of these narratives is the interactivity of my approach and the appropriate reception of these works. My research illuminates central concerns surrounding the agency of typically marginalized populations in the study of narrative, the practice of medicine, and humanity more broadly.

Eliciting “Untold Stories”: Implications of Narrative Research Methods

My approach to elicit adolescent cancer narratives has been a key component of my research. I propose that my interactive and open-ended process compiles a number of valuable techniques for research in the humanities and in clinical fields. In particular, my research demonstrates the benefits of incorporating personal interactions into the study of life writing, perceiving nonverbal expression, and using open-ended questions during clinical interviews. As I argue in sections to come, these overlapping methods, albeit not without flaw, can inform one another and provide greater insight into life narrators and patients as people.

Interactive Life Writing

Life writing scholars primarily focus on textual products rather than the contexts in which they emerge.³¹ But if life writing is both a method of creation and a genre of texts, what happens when these intertwined components are detached from one another? My study of these adolescent cancer narratives deviates from traditional life writing scholarship because I have had the privilege to access the person doing the life writing as well as their creations. Interactive research methods, I claim, can enhance understandings of these lives. After all, if “[t]ext,

³¹ Some examples of scholarship that analyze written life narratives rather than the context of creation include Chris Foss’ *Emerging from Emergence: Toward a Rethinking of the Recovery Story in Nine Contemporary Nonfiction Autism Narratives* or George Yudice’s *Testimonio and Postmodernism*.

context, and meaning are intertwined,” those who study life writing can gain great insight by analyzing how it functions as both a process and a product (Mattingly and Garro 22).

When narratives are detached from the context of their creation, scholars and clinicians tend to overlook the complexity of this communication process. Psychotherapist and cancer survivor Kathlyn Conway eloquently captures this exchange between the healthy and the ill: “[l]anguage intrudes itself between the sufferer and the listener, creating a distance from the felt experience... Yet in the very act of struggling with language [writers] do something important—they bring us into experience of frustration, loneliness, and futility that the ill and injured feel when they cannot communicate” (97). A sixteen-year-old in this study voiced her personal concerns about communication when she explained how “it’s not easy for kids to have [cancer] because we... don’t know how to express ourselves.” For adolescents to summon and process their experiences can be difficult in its own right, let alone to convey these intimacies to others. In addition, it has been widely acknowledged that there are “limits of language and literary form for representing pain, suffering, and awareness of mortality,” which likely contributes to these difficulties (Conway 3). Engagement of both parties in and outside the clinical realm can address these challenges for youth by giving adolescents space to have a voice and gain agency. Interpersonal encounters have enabled adolescent expression and helped me to better understand the individuals who live these lives and the challenges they may face in narration.

At the same time, personal interactions may bias a researcher’s attempt at objectivity and skew analysis. Autobiography scholars Sidonie Smith and Julia Watson identify how interactive presence can shape narrative itself: “[w]hen someone tells his life story before a ‘live’ audience, that audience is palpably there, soliciting, assessing, even judging the story being told. Thus, the audience directly influences the presentation of identity” (2nd ed. 77). By embracing transparency

and promoting awareness of methodological approaches, I believe, research can move beyond these potential impediments. Acknowledging researcher positionality and ethical considerations in interactive life writing is crucial to this complex narration process.

Even with the intricacy of narrative creation, interactive methods are not always appropriate; I am not advocating that all narrative studies incorporate the person creating the narrative, but there are times when this involvement can provide an additional medium for communication and enable agency through narrative expression. Literary scholar Amy Shuman's research into everyday encounters and conflicts amongst adolescents "provides a way of discussing oral narratives in terms appropriate to the adolescent's communication and in correspondence with the issues usually assigned to written texts" (13). Evaluating verbal and written narratives gives adolescents the option to express themselves in the medium they most prefer and allows each medium to inform interpretations of the other. Similarly, literary scholar Megan Sweeney performs interpersonal observation alongside textual analysis to explore reading in women's prisons, granting these women agency in the process. By inviting women to contribute their own experiences and insight into reading in prisons, she "counters women prisoners' frequent positioning as silent objects of cultural and political discourse" (*Reading is My Window* 9). Integrating women prisoners as people with voices of their own aligns with Sweeney's goals to understand the diversity of women prisoners and their various reading practices. These exemplary research methodologies model appropriate and effective involvement of real individuals that can enhance narrative understanding and, moreover, make narrative itself more accessible to historically marginalized populations. While life writing has focused primarily on narrative creations, the method I propose incorporates the real person fundamental to the process, thus acknowledging the influence of methodology on narrative expression.

Non-Verbal Perception

From a researcher's perspective, witnessing narrative creation has invaluable informed how I approach these works. The first adolescent to participate in my research instilled in me a profound appreciation for these interpersonal interactions. After this twelve-year-old adolescent told me about what he does in the hospital, his aunt encouraged him to draw a picture of his nurse. He shifted his gaze downward and said, "I'm sort of nervous." I asked him what he was nervous about and he shrugged his shoulders, mumbling "mmm" to the tune of "I don't know." In moments such as these, when words were somehow insufficient, I found that much could be gained from merely being present to observe how narratives were spoken, written, drawn, sometimes even unrealized. How might this adolescent's wandering gaze or reluctant body language complicate how one understands his words? More than his explicit admittance of nervousness, this adolescent's hesitance revealed an element of fear regarding narrative expression. Yet he did not explicitly confess to fear—there seemed to be little space in language for him to adequately do so. Observing how narrative creation emotionally impacts him in unexpressed ways reaffirms the importance of such contextualization and raises an important challenge: how can narrative and clinical studies validate the process of expression by acknowledging such visceral reactions?

My interactive approach thus presents a joint solution: by being physically present during narrative creation, clinical and non-clinical researchers can be receptive to the nonverbal communication that is so fundamental to human expression, be it intentional or not. As physician and anthropologist Arthur Kleinman observes, "facial expression, tone of voice, posture, body movements, gait, and, especially, the eyes" each illuminate aspects of coping with chronic illness in literally inexplicable ways (44). Although interactive research is not a new concept in the

social sciences,³² its relative absence in humanistic fields is unacceptable. I want to propose that interactivity can contribute positively to narrative research, particularly as it pertains to illness. Nonverbal narratives can enhance understandings of illness experiences and, more importantly, the person living through them. In addition, these interpersonal encounters challenge normative and able-bodied narrative methods that may exclude and silence individuals. With inarticulate children, for example, childhood studies scholar Allison Boggis describes how expression often “exceed[s] ways of hearing, knowing, and listening,” for “[v]oice’ clearly occurred in spoken utterances, but also in silence, behaviour, body language and facial expression.” With my physical presence, I sought to be perceptive of unconventional communication. Although this method is not without flaws, since such interpretations are fundamentally subjective and often cannot be represented in published pathographies, nonverbal expression offers an alternate communication method to those for whom traditional writing is inadequate or even inaccessible.

Being receptive to nonverbal expression is of particular importance to studying narratives of youth and practicing pediatrics, for “much of the pediatric story emerges from nonverbal communication on the part of the child” (DasGupta, *Between Stillness and Story* 1386). Pediatrician and writer Sayantani DasGupta accounts for why youth, who may not have the vocabulary to describe pain or confront emotion,³³ are often unable to fully express themselves through language: “[v]ery young children are developmentally unable to access and to use language in the same manner as adults, but even older children are often unable to articulate their experiences, because of their social voicelessness” (*Between Stillness and Story* 1386). She also

³² While interactive, ethnographic research is prominent in social sciences, I advocate for these methods to be borrowed and adapted by humanistic fields like disability and narrative studies, which devote particular attention to individuals living in today’s society.

³³ This problem certainly arises in adult populations as well due to language barriers or impairing ailments, but it has been less acknowledged and tackled in the practice of pediatrics.

proposes that “social voicelessness” in adolescence may be attributed to “a manifestation of internal emotional struggles” that is projected into social communication, which heightens the importance of witnessing nonverbal expression (DasGupta, *Between Stillness and Story* 1386). Health practitioners must attend to these lives with a keen awareness of the range in self-telling modes. Through this “narrative consciousness,” as I call it, clinicians can gain insight into their pediatric patients, and narrative scholars can better understand youth as life writers. Interactive life writing responds to how humans communicate in and outside of language, thereby increasing the accessibility of narrative expression and allowing otherwise vulnerable subjects like youth to have a literal and figurative, verbal and non-verbal, voice.

By uniting extratextual observation with close analysis of language used to express illness, research can value the *real “I,”* the person living the life (in this case, the adolescent with cancer) and the *narrating “I”* that expresses this life while still studying the *narrated “I.”* Bringing the *real “I”* and the *narrating “I”* into conversation with one another and with the *narrated “I”* enables interactive methodology to gain additional insight into an individual through the inevitable “autobiographical gap” (Charon, *Honoring Stories of Illness* 90). Dual perspectives better inform understandings of the *real “I”* and the *narrating “I”* as well as the narrative and the person as a whole. Since these real people are central to the practices of life writing and medicine, it becomes imperative to interact with these individuals, to empower and perceive the various ways they communicate.

Open-Ended Questions

The value of open-ended questions for encouraging such communication became especially clear to me when adolescents challenged my expectations with deviating responses. These answers resisted the normal scripts readily available for discussing illness and, whether

consciously or not, always did so in divergent and unforeseen ways. When I asked Tabitha what she liked about her cancer, she told me she valued how “[i]t was a rare one, that’s pretty cool.” I asked her why, and she explained, “[b]ecause they haven’t seen it before, not a lot of people get it.” The irony of her exclamation was jarring to me: Tabitha valued the rarity of her cancer because doctors had not encountered it, but this fact meant her chance of survival is that much slimmer. She found pride in her rare diagnosis, one likely accompanied by a poor prognosis, and strikingly accepted cancer as her own—a claim she was entirely entitled to make.

If I had not asked her what she liked about cancer, Tabitha may never have voiced her appreciation that cancer makes her feel unique: often, “[e]xpectations of particular kinds of cancer stories act as constraints on the speakable, and there is little space to tell, or hear, the truth about the experience of illness” (Segal, *Cancer Experience and Its Narration* 301). In an effort to overcome these constraints, I structured conversations around open-ended questions, a more responsive method for narrative research and clinical practice. Studies have found that in medical interviews guided by open-ended questioning rather than prescribed conversation, patients provide more clinically relevant information (Takemura et al. 151). Without imposing any anticipated response, these questions allow patients to respond freely and share necessary details within the same amount of time. With my own research questions, I made an effort not to make assumptions about what it is like to have cancer as an adolescent. Instead of predicting that Tabitha would despise cancer, I inquired into what she did and did not like about cancer.

The liberties allowed by open-ended questions optimize patient agency—to a certain extent, at least. Interviews where “an informant tells an interviewer the story of her life” are inherently restrictive no matter what type of questioning is used because “power relations between the teller and recorder/editor are often asymmetrical” (Smith and Watson, 1st ed. 191).

The very nature of this narrative occasion thereby hinders an adolescent's agency. In addition, "[a]lthough this structure gives the respondent more freedom in crafting an answer, it also increases the cognitive effort" by affording individuals a potentially overwhelming amount of space to fill with their responses (Ballou 547). Nevertheless, open-ended questions can empower adolescents within the constraints of the medical encounter and provide greater narrative insight, for much can be learned from how patients choose to express themselves without inhibition.

By highlighting the interactivity, nonverbal expression, and open-ended questions in this research, I am not saying that these techniques are not already in use but rather, I wonder how they can become more commonplace in humanities and medicine. Life writing scholar G. Thomas Couser recognizes the value of these methods, for they can be an important caveat to life writing: "[p]roperly conceived and carried out (admittedly, a large qualifier), life narrative can provide the public with controlled access to lives that might otherwise remain opaque or exotic to them" (*Disability, Life Narrative, and Representation* 533). With this in mind, I focus my attention in the next section on what can be gained from narrative insight into the lives of adolescents with cancer.

Listening to "Unheard Lives": Implications of Adolescent Cancer Narratives

The adolescent cancer narratives collected in this research represent a collection of works with important implications for the fields of narrative studies and medicine. As told through different media such as writing, drawing and speaking, these works emphasize the importance of making room for varied self-expression. As I will show in this section, adolescent narratives also give voice to experiences that can prepare and inform health professionals in medical education and clinical practice.

Multimodality

Through speaking, writing, and drawing their narratives, adolescents with cancer reveal what insight can be gained through multiple modes. If an important goal for studying life writing is to understand the individual living the life, how can multimodality provide greater insight into the unheard lives of adolescents with cancer? Since “[a] multimodal approach to representation offers a choice of modes,” I classify these narratives as multimodal to emphasize that they represent the same life through a variety of different media (Kress 93). When I sat down with Mary at her outpatient doctor’s appointment, she spoke openly about her experiences with cancer and her steadfast Christian faith. She also filled a blank storybook with drawings, focusing on select images to represent milestones in her trajectory with cancer. What insight may have been lost if I had never spoken to Mary and had relied entirely on her visual narrative? Or, conversely, how might I have interpreted our spoken conversation differently without the drawings to supplement it? The discrepancy between experiences shared through image and spoken word urges the importance of being receptive to multiple media, for “[w]ritten autobiographies represent only a small if revealing part of a much larger phenomenon, the self-narration we practice every day” (Eakin, *Living Autobiographically* 34). Without our conversation, it would have been difficult to fully appreciate the ribbon Mary drew on the cover of her narrative, revealing the centrality of her faith to her experiences with cancer.

Multimodality can accommodate diverse preferences within the adolescent population and resist common assumptions about these individuals. Integrating multimodality in literacy education, for example, has been effective because “new media provide[s] multiple ‘ways in’ for young people who are kept at the margins of the composing process in schools” (Vasudevan 254). Literacy scholar Lalitha Vasudevan urges that we use multimodality to “make heard the

voices, images, words, and worlds of adolescent,” appreciating variety in expression and better enabling adolescent agency in the process (256). Educator Kathy Mills similarly challenges societal assumptions that all adolescents are technologically savvy and uses multiple forms of media to adjust to the needs of adolescents with varying technological abilities. By enabling alternate methods of learning, she is more effectively able to “move [students] beyond the known to the new” (44). Multimodality, then, can be an effective technique for agentic endeavors.

No single medium is sufficient to learn about adolescent experiences with cancer. To make room for adolescent agency, multiple media must be made available for adolescents to express themselves however they are most comfortable. Different stories are told through different media, and my analysis has benefited greatly from exploring these various experiences.

Since I was introduced to these adolescents within the medical realm, a number of clinical implications to these adolescent cancer narratives stand out to me. With my personal interests in medicine, I want to turn my attention now to some of the more overt ways that these narratives can positively contribute to medical education and clinical practice. Although I focus especially on implications for health care, it is important to bear in mind that many of these notions are cross-disciplinary and may also be relevant to humanistic studies of medicine.

Medical Education

When health practitioners pose open questions to patients, carefully listening to their responses allows important ideas to surface through spoken words and the silences that separate them. Physician and narratologist Rita Charon, who is also a pioneering figure in narrative medicine, claims that this narrative intimacy is vital to encounters between health providers and their patients: “when told freely and heard expertly, the self-telling that occurs in medical settings can... give voice to body, relation, and narratively achieved identity” (*Honoring Stories*

of Illness 78). If open-ended questions enable freedom in self-telling, how can medical education encourage health practitioners to hear “expertly”? In response to this challenge, Arthur Kleinman advocates for “the interpretation of narratives of illness experience” (xiii). When patients present their illnesses and their lives, health practitioners bear the responsibility of making sense of these expressions. What better way to prepare for clinical encounters with adolescents than through experiencing the cancer narratives they create? Adolescent cancer narratives can help clinicians enhance and embrace this narrative intimacy.

I believe that these narratives can and should change conversations with health providers to more effectively attend and adapt to each patient. When asked about what he would do or say if cancer was a person, one adolescent said simply that he “would try to be friendly. I wouldn’t be having it thinking bad about itself.” I was caught off-guard by his response. I never anticipated such kind and thoughtful sentiments toward cancer, especially when most adolescents expressed violent animosity in response to this question. This adolescent did not despise his cancer as an enemy, though; perhaps as he personified cancer, his manners took precedence over any antagonistic feelings he had against the disease. Maybe he proudly recognized cancer as a part of him and, in doing so, resisted perceiving it as an evil. For training health professionals, his diverging viewpoint demands for broader systemic changes in the language used to confront experiences of illness; after all, our language choices can impact how we conceive of a person’s identity, selfhood, and understanding of illness. Current clinical language, which often associates battle metaphors with cancer, is therefore inadequate. This vocabulary leaves no room for other perspectives, and it may be detrimental to those who are more accepting of cancer and consider it a part of their self. As evidenced by how this adolescent turns to courtesy instead of combat, his relationship to cancer is far more complex than that of good and evil and must be treated as such.

Although illness narratives have been implemented throughout various stages of medical education,³⁴ they have yet to be used to specifically educate health practitioners in pediatrics. By raising awareness of diverse adolescent cancer experiences, these works can expose health professionals to the first-hand perspectives of the ill and prepare clinicians to be more attuned to the patient experiences they do encounter. Narrative can help health professionals to recognize and adjust to the personal trajectory of each adolescent with cancer. Furthermore, these narratives can impact clinical care at large to focus more on the experiences of those living with disease. These stories and their creation can change medical education and, as I argue in the following section clinical practice, by encouraging greater attention to patients as people rather than merely to the diseases that inhabit them.

Clinical Practice

Beyond medical education, health practitioners can also use adolescent narratives such as these to personalize their care for each individual. By revealing gaps or misunderstandings in patient knowledge of cancer and treatment, these narratives become clinically useful to improve communication and provide clarification accordingly. For those who struggle to find anything to appreciate about chemotherapy, clinicians can ensure that adolescents at least understand the long-term purpose of treatment. This enhanced awareness can potentially help validate the side effects of treatment so youth can better cope with these experiences.

Since these narratives can portray an adolescent's unique values and preferences, they can also be used to personalize care and treatment when possible. When I asked adolescents whether cancer had changed their life, I admit that I anticipated they would respond

³⁴ See Arno Kumagai, *A Conceptual Framework for the Use of Illness Narratives in Medical Education*, Johanna Shapiro et. al, *Just a Spoonful of Humanities Makes the Medicine Go Down: Introducing Literature into a Family Medicine Clerkship*, and Rita Charon et. al, *Literature and Medicine: Contributions to Clinical Practice*.

affirmatively. Instead, two of the twenty-five adolescents said that cancer had not changed their lives. One explained, “No... cause I can still like play sports. And I’m still like really good at them. I can do pretty much everything that I...well I can do most of the stuff that I did before I had cancer.” What struck me about his response was that not only did he deny assumptions that cancer is life changing, but he also reflected on what he most values: his physical abilities. If this adolescent especially wants to retain physical capabilities, can clinicians use this information to better care for him? When there are multiple ways to administer treatment, understanding personal adolescent preferences may allow health providers to privilege physical capabilities if possible (although it may not always be). Narrative can be instrumental in revealing unique adolescent preferences, and such alterations in care can better support each individual’s needs.

As I have explored in this chapter, my methods and these narratives have broader implications that extend beyond this thesis. Although these techniques are not fundamentally novel approaches, my research combines and extends these methods in new ways. My encounters with these adolescents and the narratives they have created provide a number of ideas to be taken into consideration for further research in clinical and non-clinical fields. While I have outlined some of the scholarly contributions that my research presents, these ideas are merely an introduction to the vast potential for growth that lies at the intersection of narrative studies and medicine. These poignant vignettes draw attention to the urgency of moving towards research methods and analysis that make room for narrative scholars and health professionals alike to appreciate and act upon untold stories and unheard lives.

Conclusion

“In reality you don’t know... you don’t anything what I’m going through... you just know the story.”

—Andy, fifteen-year-old male

As our conversation was nearing an end, I asked Andy about what he would want the adults in his life to know about what it is like to have cancer. He paused for a moment, and then said, “that it’s hard.” Andy explained how “some of them [adults] will say, ‘oh I know exactly what you’re going through,’ but in reality you don’t know.” He described cancer as an unfathomable experience, beyond the realm of understanding for others: “[t]hey’re not going to know about it unless they get it, unless they...yeah unless they get it, unless they get the disease.” But if understanding what adolescents with cancer are going through is an unattainable goal for those without the disease, then what can be gained from knowing “just...the story”?

Andy’s perception that stories contribute to (mis)understandings about adolescent cancer is significant, especially considering that he seemed to criticize the very premise of my project. Andy used the term story in a way that resonates with the nature of these adolescent narratives, which similarly share individual experience through a familiar narrative structure. Andy’s accusation begs the question: why should we use stories to better understand adolescents with cancer? And, concurrently, what limitations to narrative expression may inhibit such understandings? Andy sharply criticized how adults use stories to make universal assumptions about adolescents and the “cancer experience.” He suggested that when stories propagate, people tend to use experiences they are familiar with to extrapolate those of other adolescents. Although “they’re just trying to connect to you,” as thirteen-year-old Mary put it, this response has the latent effect of disregarding and even disrespecting individual adolescent experiences. For those living with cancer, such presumptuous reactions can be frustrating.

Upon recognizing how good intentions can go astray, I have consciously strived to analyze both collective and individual adolescent experiences. Achieving this delicate balance has been essential to my goals of optimizing adolescent agency, especially in a medical setting that often challenges this very entitlement. Even though stories run the risk of propelling forward stereotypes about adolescent cancer, I have drawn attention to their potential to “remind everyone of the multiplicity of perspectives and realities that make life what it is” (Frank, *Necessity and Dangers of Illness Narratives* 166). I have highlighted common perspectives but also pointed to uncommon ideas that deviate, resist, and even challenge these trends. My thesis thus disproves the notion of a singular “adolescent cancer experience,” for these diverse experiences exemplify “the multiplicity of perspectives and realities” associated with adolescent cancer. Each individual’s experience with cancer is subjective by nature.

With this multiplicity of adolescent cancer experiences, agency once again emerges at the forefront. This thesis has unveiled the need, even the urgency, to make life writing more accessible so adolescents can, if they so choose, share their own perspectives about their experiences with cancer. Allowing discourse to unfold without including these voices is exclusive and unacceptable; in response, this research empowered adolescents by creating a space for them to give voice to their own lives with cancer. Ultimately, the process of narrative creation has been a way for adolescents with cancer to somewhat take control of their stories and, by extension, this part of their lives. By enabling and exploring these untold stories, my thesis reaffirms “the need for patients to exercise agency through narrative in order to achieve a more successfully managed cancer care environment” (O’Hair, Scannell, and Thompson 414). For an adolescent population that already has limited agency, this method of empowerment can be especially effective. Cancer, in many ways, remains a mystery to those in and outside of the

medical profession; in light of this ambiguity, we must devote attention to the ways that adolescents choose to make sense of this disease and themselves. The adolescent self is complex, no doubt, but cancer's arrival affects many facets of the self in unpredictable ways. Narrative illuminates elements of the adolescent self with cancer that often go unnoticed. Rather than impose our own understandings about what it is like to have cancer in adolescence, it is our responsibility to be receptive to adolescents living through these very experiences.

Andy is indeed correct, though: I can't ignore the limitations to understanding individuals through narrative. After all, these narratives are just representations—of real people living real lives, but representations nonetheless. As Frank states rather simply, “[i]llness narratives are not illnesses” (*Rhetoric of Self-Change* 41). Despite the inevitable variance between living experience and its narrative representation, expression remains the only way we can begin to understand experiences that we ourselves do not live: “[w]hile [adolescent] writing may only be a whisper alluding to what they have experienced, it still can be considered a representation of their voice” (Jones 13).

Thus, there is undeniable power to the stories that these voices tell. I want to claim that these stories can be used to oppose widespread misconceptions about adolescent cancer experiences. Narrative can resist unwarranted assumptions built upon the notion that there is “uniformity of experience within a diagnostic category” (Hawkins, *Reconstructing Illness* 5). One adolescent seemed cognizant of this power when he refused to advise others with cancer: “I think, I'd just tell them of, like, my experiences with... of like going through the diagnosis to treatment but I wouldn't really suggest anything to them because like all the different cancers are, like, all the different experiences are different so like, I'd probably just share with them my experience.” He understood that difference is inherent in adolescent cancer experiences. Each

adolescent is unique, and so too are their experiences with cancer. The best way to help others is to share personal experiences, all the while recognizing that no two lives are ever quite the same.

In many ways, this thesis has just begun to scratch the surface of childhood cancer experiences, as told through narrative. Much remains to be understood about narrative expression and reception amongst adolescents. How does the narrative creation process affect adolescents that engage in it, and what impact can receiving these narratives have on others with cancer? Further research should explore whether adolescents who share and receive these works perceive narrative communication to be a therapeutic opportunity, and how such activities can be incorporated into their professional care. While I enabled adolescents to write, draw, and speak, other mediums must also be offered to maximize accessibility— if we are to truly find ways to optimize the agency of more adolescents, that is. I am thinking, for example, of the vast array of Internet and social media platforms that use online interaction to foster communities. Adolescents may be more comfortable with other means of expression such as social media platforms. From Facebook statuses to 140-character tweets, instagram selfies to YouTube webcam videos, social media outlets may enable more natural self-telling for young populations. If pathography has “the capacity to transform that experience in ways that heal,” I wonder how these other genres of expression may affect adolescents who rely so heavily upon them (Hawkins, *Pathography* 129). And with cancer representing a constellation of diseases with different treatments, engaging more adolescents and exploring the effects (if there are any) of various protocols and stages in treatment would also illuminate the multiplicity of realities within cancer. Even looking beyond the adolescent population, pediatric cancers affect children and young adults with untold stories of their own. These voices have every right to be heard; more exploration of best practices to enable the agency of these youth is of great import.

With vast avenues for future research and my own impassioned dedication to youth with cancer, I believe that this conclusion functions as a gateway for further investigation more than it provides closure to this research. In my introduction, I asserted that adolescent cancer narratives fill an important void in illness narratives and urged that “[t]he stories we might tell of the experience, if we wish to tell a story at all, do need to be honored, even if they are—especially if they are—the ones no one really expected to hear.” (Segal, *Cancer Experience and Its Narration* 313). This notion, to me, encapsulates much of what I have strived to achieve in this thesis. Certainly, adolescents experience cancer differently, which one may have expected from the start. But much of the discovery through narrative arises in moments of the unexpected: surprising emotions, frustrations of being ill, even the joys of having cancer. While the narratives I have collected for this research have importantly begun to fill this void, “we have not ‘finished’ telling cancer stories, nor have we exhausted their potential as a genre” (Schultz and Holmes xiv). Literary scholars Jane Schultz and Martha Holmes write about the value of this genre quite eloquently yet eerily: “[l]ike the illness itself, cancer stories are protean and self-replicating, unpredictable, latent and then rampant, surprising and sometimes surprisingly beautiful, funny, desperate, and simply human” (xiv).

The simple humanity at the core of adolescent cancer narratives is what we gravitate towards; it is what has most moved me. Alongside deep sighs, distant gazes, and quiet voices, many adolescents shared smiles of joy and bursts of laughter with me. These narratives remind us of the people at the heart of these experiences. We have a responsibility to make room for these stories to emerge, to receive and bear witness to these unheard lives of adolescents with cancer—all the while remembering that there is more to these individuals than “just...the story.”

Works Consulted

- Abbott, H. Porter. *The Cambridge Introduction to Narrative*. Cambridge, UK: Cambridge UP, 2002. Print.
- Albritton, K., and W.a. Bleyer. "The Management of Cancer in the Older Adolescent." *European Journal of Cancer* 39.18 (2003): 2584–2599. Web. 11 Mar. 2014.
- Atkinson, Sarah, and Sara Rubinelli. "Narrative in Cancer Research and Policy: Voice, Knowledge and Context." *Critical Reviews in Oncology/Hematology* 84 Suppl 2 (2012): S11–6. Web. 6 Jan. 2014.
- Back, Anthony et al. "Humanism in Oncology: What Makes Education in Communication Transformative?" *Journal of Cancer Education* 24.2 (2009): 160–2. Web. 24 Feb. 2014.
- Ballou, Janice. "Open-Ended Question." *Encyclopedia of Survey Research Methods* (2008) SAGE Publications. Web. 24 Feb. 2014.
- Bauby, Jean-Dominique. *The Diving Bell and the Butterfly*. New York: A.A. Knopf, 1997. Print.
- Beale, Estela A., Walter F. Baile, and Joann Aaron. "Silence Is Not Golden: Communicating with Children Dying From Cancer." *Journal of Clinical Oncology* 23.15 (2005): 3629–31. Web. 14 July 2013.
- Bernard, H. Russell. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. N. p., 2006. Print.
- Bissell, Paul, Carl R. May, and Peter R. Noyce. "From Compliance to Concordance: Barriers to Accomplishing a Re-Framed Model of Health Care Interactions." *Social Science & Medicine* 58.4 (2004): 851–862. Web. 14 Feb. 2014.
- Blondis, Marion Nesbitt, and Barbara E. Jackson. *Nonverbal Communication with Patients: Back to the Human Touch*. New York: Wiley, 1977. Print.

- Boggis, Allison. "Deafening Silences: Researching with Inarticulate Children." *Disability Studies Quarterly* 31.4 (2011). n. pag. Web. 14 February 2014.
- Booher, Amanda K. "Defining Pistorius." *Disability Studies Quarterly* 31.3 (2011). n. pag. Web. 16 February 2014.
- Brewster, Arlene Barbara Blank. *Children's Understanding of Illness*. Diss. University of Michigan, 1980. Print.
- Brownley, Martine Watson, and Allison B. Kimmich. *Women and Autobiography*. Wilmington, DE: SR, 1999. Print.
- Brueggemann, Brenda Jo, and Debra Modellmog. "Coming-Out Pedagogy : Risking Identity in Language and Literature Classrooms." *Pedagogy* 2.3 (2002): 311–335. Print.
- Bruner, Jerome S. *Making Stories: Law, Literature, Life*. New York: Farrar, Straus, and Giroux, 2002. Print.
- . "The 'Remembered' Self." *The Remembering Self: Construction and Accuracy in the Self-Narrative*. Ed. Ulric Neisser and Robyn Fivush. Cambridge: Cambridge UP, 1994. Print.
- Cahill, Lisa Sowle. "'Embodiment' and Moral Critique: A Christian Social Perspective." *On Moral Medicine: Theological Perspectives in Medical Ethics*. Eds. Stephen E. Lammers and Allen Verhey. Grand Rapids, Mich.: Eerdmans, 1998. Print
- Carlick, A., and F. C. Biley. "Thoughts on the Therapeutic Use of Narrative in the Promotion of Coping in Cancer Care." *European Journal of Cancer Care* 13.4 (2004): 308–17.
- Chamberlain, Shannin. *My ABC Book of Cancer*. San Francisco: Synergistic, 1990. Print.
- Charmaz, Kathy. "Stories and Silences: Disclosures and Self in Chronic Illness." *Qualitative Inquiry* 8.3 (2002): 302–328. Web. 7 Nov. 2013.

- Charon, Rita et al. "Literature and Medicine: Contributions to Clinical Practice." *Annals of Internal Medicine* 122.8 (1995): 599–606.
- Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. Oxford: Oxford UP, 2006. Print.
- . "Narrative Medicine : Attention, Representation, Affiliation." *Narrative* 13.3 (2014): 261–270. Print.
- . "Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust." *Revista de la Facultad de Ciencias Médicas (Córdoba, Argentina)* 69.2 (2012): 75–6.
- . "What to Do with Stories: The Sciences of Narrative Medicine." *Canadian Family Physician* 53 (2007): 1265–1267. Print.
- Conway, Kathlyn. *Illness and the Limits of Expression*. Ann Arbor: University of Michigan, 2007. Print.
- Couser, G. Thomas. "Autopathography: Women, Illness, and Lifewriting." *Women and Autobiography*. Eds. Martine Watson Brownley and Allison B. Kimmich. Wilmington, DE: SR, 1999. Print
- . *Recovering Bodies: Illness, Disability, and Life-writing*. Madison: University of Wisconsin, 1997.
- . *Signifying Bodies: Disability in Contemporary Life Writing*. Ann Arbor: University of Michigan, 2009. Print.
- . *Vulnerable Subjects: Ethics and Life-Writing*. 2004.
- . "Disability, Life Narrative, and Representation." Davis 531-534.
- DasGupta, Sayantani. "Between Stillness and Story: Lessons of Children's Illness Narratives." *Pediatrics* 119.6 (2007): e1384–91. Web. 21 June 2013.

- Dasgupta, Sayantani. "Stories Matter: Narrative, Health and Social Justice." *Conexión Pediátrica* 5 (2012): 1–4. Print.
- DasGupta, Sayantani, and Marsha Hurst. *Stories of Illness and Healing: Women Write Their Bodies*. OH: Kent State UP, 2007. Print.
- Davis, Lenard J. "Constructing Normalcy." Davis 3-20.
- Davis, Lenard J., ed. *The Disability Studies Reader*. New York: Routledge, 2010. Print.
- DeMaria, Anthony N. "Adherence, Compliance, Concordance, or the Lack Thereof." *Journal of the American College of Cardiology* 59.12 (2012): 1120–1. Web. 14 Feb. 2014.
- DeShazer, Mary K. *Fractured Borders: Reading Women's Cancer Literature*. Ann Arbor: University of Michigan, 2005. Print.
- Desserich, Brooke, and Keith Desserich. *Notes Left Behind*. New York: William Morrow, 2009. Print.
- Douglas, Kate. *Contesting Childhood: Autobiography, Trauma, and Memory*. New Brunswick, NJ: Rutgers UP, 2010. Print.
- Drew, Sarah. "'Having Cancer Changed My Life, and Changed My Life Forever': Survival, Illness Legacy and Service Provision Following Cancer in Childhood." *Chronic Illness* 3.4 (2007): 278–95. Web. 1 Nov. 2013.
- Dwyer, Ann. "Dexter Teenager with Inoperable Brain Tumor Asks Community to Help Charity" *Ann Arbor.com*. The Ann Arbor News, Web. 13 Nov. 2009.
- Eakin, Paul John. *How Our Lives Become Stories: Making Selves*. Ithaca, NY: Cornell UP, 1999. Print.
- . *Living Autobiographically: How We Create Identity in Narrative*. Ithaca, NY: Cornell UP, 2008. Print.

- . *The Ethics of Life Writing*. Ithaca, NY: Cornell UP, 2004. Print.
- Engel, George. "The Need for a New Medical Model : A Challenge for Biomedicine." *Science* 196.4286 (1977): 129–136. Print.
- Foucault, Michel. *The Birth of the Clinic; an Archaeology of Medical Perception*. New York: Pantheon, 1973. Print.
- Frank, Arthur W. "Illness and Autobiographical Work : Dialogue as Narrative Destabilization." *Qualitative Sociology* 23.1 (2000): 135–156. Print.
- . "The Necessity and Dangers of Illness Narratives, Especially at the End of Life." Gunaratnam and Oliviere 161-175.
- . *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago, 1995. Print.
- . "What Is Dialogical Research, and Why Should We Do It?" *Qualitative Health Research* 15.7 (2005): 964–74. Web. 15 Aug. 2013.
- Fesler, Rene. *Alicia's Update: A Mother's Memoir of Pediatric Cancer*. N.p.: Xlibris, 2009. Print.
- Foss, Chris. "Emerging from Emergence: Toward a Rethinking of the Recovery Story in Nine Contemporary Nonfiction Autism Narratives." *Disability Studies Quarterly* 29.2 (2009): n. pag. Web. 14 Feb. 2014.
- Gaines, Atwood D, and Robbie Davis-Floyd. "On Biomedicine." *Encyclopedia of Medical Anthropology*. Eds. Carol and Melvin Ember. Yale: Human Relations Area Files, 2003. Web. 2 March 2014.
- Gardner, Kirsten E. "Disruption and Cancer Narratives: From Awareness to Advocacy." *Literature and Medicine* 28.2 (2009): 333–50.

- Garland-Thomson, Rosemarie. "The Politics of Staring: Visual Rhetorics of Disability in Popular Photography." *Disability Studies: Enabling the Humanities* 189-205. Print.
- Gilmore, Leigh. *The Limits of Autobiography: Trauma and Testimony*. Ithaca, NY: Cornell UP, 2001. Print.
- Glover, Carol. *Loving Hannah: Childhood Cancer from the Other Side of the Bed*. Rockland, Me: Maine Authors, 2011. Print.
- Gould, Elaine, and Ethel Mitty. "Medication Adherence Is a Partnership, Medication Compliance Is Not." *Geriatric Nursing (New York, N.Y.)* 31.4 290–8.
- Granger, Dené. "A Tribute to My Dyslexic Body, As I Travel in the Form of a Ghost." *Disability Studies Quarterly* 30.2 (2010). n. pag. Web. 03 March 2014.
- Grealy, Lucy. *Autobiography of a Face*. Boston: Houghton Mifflin, 1994. Print.
- Greenhalgh, Trisha, and Brian Hurwitz. "Why Study Narrative?" *BMJ* 318.January (1999): 48–50. Print.
- Greer, Jason Paul. *Very Much Better: A Cancer Memoir By a Boy Who Lived*. N.p.: Acs, LLC, 2011. Print.
- Gunaratnam, Yasmin, and David Oliviere, eds. *Narrative and Stories in Health Care: Illness, Dying, and Bereavement*. Oxford: Oxford UP, 2009. Print.
- Gunaratnan, Yasmin. "Narrative Interview and Research." Gunaratnam and Oliviere 47-61.
- Gygax, Franziska. "Life Writing And Illness:" *Prose Studies* 31.3 (2009): 291–299. Web. 31 Dec. 2013.
- Haraway, Donna. "Chapter 4: A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late 20th Century." *The International Handbook of Virtual Learning Environments*. Eds. J. Weiss et al. Netherlands: Springer, 2006. 117–158. Web.

- Harden, Jane. "Language, Discourse and the Chronotope: Applying Literary Theory to the Narratives in Health Care." *Journal of Advanced Nursing* 31.3 (2000): 506–12.
- Hawkins, Anne Hunsaker. *Reconstructing Illness: Studies in Pathography*. 2nd ed. West Lafayette, IN: Purdue UP, 1999. Print.
- . "Pathography: Patient Narratives of Illness." *The Western Journal of Medicine*. 171.2 (1999): 127–9.
- Holstein, James A., and Jaber F. Gubrium. *Varieties of Narrative Analysis*. Los Angeles: Sage, 2012. Print.
- Hyden, Lars-Christer. "Illness and Narrative." *Sociology of Health and Illness* 19.1 (1997): 48–69.
- Jaarsma, Pier and Stellan Welin, "Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement?" *Health Care Anal* 20.1 (2012): 20-30. Web.
- Jenkins, Henry. *The Children's Culture Reader*. New York: New York UP, 1998. Print.
- Johnstone, Christopher J. "Disability and Identity: Personal Constructions and Formalized Supports." *Disability Studies Quarterly* 24.4 (2004). n. pag. Web. 17 February 2014.
- Jones, Barbara L., Jessica Parker-Raley, and Amanda Barczyk. "Adolescent Cancer Survivors: Identity Paradox and the Need to Belong." *Qualitative Health Research* 21.8 (2011): 1033–40. Web. 7 Oct. 2013.
- Jones, Melissa M. *Whisper Writing: Teenage Girls Talk about Ableism and Sexism in School*. New York: P. Lang, 2004. Print.
- Jurecic, Ann. *Illness as Narrative*. Pittsburgh: University of Pittsburgh, 2012. Print.

- Kameny, Rebecca R., and David J. Bearison. "Illness Narratives: Discursive Constructions of Self in Pediatric Oncology." *Journal of Pediatric Nursing* 14.2 (1999): 73–9.
- Kehily, Mary Jane. "Self-Narration, Autobiography and Identity Construction." *Gender and Education* 7.1 (1995): 23–32. Web. 10 Dec. 2013.
- Kellerman, Jonathan. *Psychological Aspects of Childhood Cancer*. Springfield, IL: C.C. Thomas, 1980. Print.
- Kelly, Michael P., and Hilary Dickinson. "The Narrative Self in Autobiographical Accounts of Illness." *Sociological Review* 45.2 (1997): 254–278.
- Khorana, Alok A., Michelle Shayne, and David N Korones. "Can Literature Enhance Oncology Training? A Pilot Humanities Curriculum." *Journal of Clinical Oncology* 29.4 (2011): 468–71. Web. 12 Aug. 2013.
- Kleinman, Arthur. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic, 1988. Print.
- Korsch, Barbara M., Barbara Freemon, and Vida Francis Negrete. "Practical Implications of Doctor-Patient Interaction Analysis for Pediatric Practice." *American Journal of Diseases of Children* 121.2 (1971): 110–4.
- Kress, Gunther R. *Multimodality: A Social Semiotic Approach to Contemporary Communication*. London: Routledge, 2010. Print.
- Kumagai, Arno K. "A Conceptual Framework for the Use of Illness Narratives in Medical Education." *Academic Medicine* 83.7 (2008): 653–8.
- Linton, Simi. "Reassigning Meaning." Davis 223-236.
- Lorde, Audre. *The Cancer Journals*. Argyle, NY: Spinsters, Ink, 1980. Print.

- Marchiano, Melinda. *Grace: A Memoir: A Child's Intimate Journey through Cancer and Recovery*. San Luis Obispo, CA: Happy Quail, 2010. Print.
- Mathieson, Cynthia M, and Henderikus J. Stam. "Renegotiating Identity : Cancer Narratives." *Sociology of Health & Illness* 17.3 (1995): 283–306. Print.
- Mattingly, Cheryl. "4 : Performance Narratives in the Clinical World." *Narrative Research in Health and Illness*. Eds. Brian Hurwitz et al. (2004): 73–94. Print.
- Mattingly, Cheryl, and Linda C. Garro. *Narrative and the Cultural Construction of Illness and Healing*. Berkeley: University of California, 2000. Print.
- Mauss, Marcel. "Techniques of the Body." *Economy and Society* 2.1 (1973): 70-88. Print.
- Miller, Peggy J. et al. "Narrative Practices and the Social Construction of Self in Childhood." *American Ethnologist*. 1989.
- Mills, Kathy A. "Shrek Meets Vygotsky: Rethinking Adolescents' Multimodal Literacy Practices in Schools." *Journal of Adolescent & Adult Literacy* 54.1 (2010): 35–45. Web. 25 Feb. 2014.
- Milner, Laura A. "Voice Giving (Way)." *Disability Studies Quarterly* 31.3 (2011). n. pag. Web. 16 January 2014.
- Mitchell, David T., and Sharon L. Snyder. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan, 2001. Print.
- Mukherjee, Siddhartha. *The Emperor of All Maladies: A Biography of Cancer*. New York: Scribner, 2010. Print.
- Neisser, Ulric, and Robyn Fivush. *The Remembering Self: Construction and Accuracy in the Self-narrative*. Cambridge: Cambridge UP, 1994. Print.

- Nelson, Hilde Lindemann. *Damaged Identities, Narrative Repair*. Ithaca: Cornell UP, 2001. Print.
- Neville, Kathleen L. *Mature Beyond Their Years: The Impact of Cancer on Adolescent Development*. Pittsburgh, PA: Oncology Nursing, 2000. Print.
- O’Hair, Dan., Denise Scannell, and Sharlene Thompson. “Agency Through Narrative: Patients Managing Cancer Care in a Challenging Environment.” *Narratives, Health, and Healing: Communication Theory, Research, and Practice*. Eds. Lynn M. Harter, Phyllis M. Japp, and Christina S. Beck. New York: Routledge, 2008. Print.
- Ousager, Jakob, and Helle Johannessen. “Humanities in Undergraduate Medical Education: A Literature Review.” *Academic Medicine* 85.6 (2010): 988–998. Print.
- Pantell, Robert H et al. “Physician Communication with Children and Parents.” *Pediatrics* 70.3 (2013): 396–402. Print.
- Parry, Carla. “Embracing Uncertainty: An Exploration of the Experiences of Childhood Cancer Survivors.” *Qualitative Health Research* 13.2 (2003): 227–246. Web. 7 Oct. 2013.
- “Pediatric Cancer Patient Stories.” *The Children’s Hospital of Philadelphia Cancer Center*. Web. 11 May 2013.
- Perusek, David. “Cancer, Culture, and Individual Experience: Public Discourse and Personal Affliction.” *Ethos* 40.4 (2012): 476–506. Web. 6 Jan. 2014.
- Petersen, Alan R., and Robin Bunton. *Foucault, Health and Medicine*. New York: Routledge, 1997. Print.
- Herndl, Diane Price. “Disease versus Disability : The Medical Humanities and Studies Disability.” *Conference on Disability Studies and the University* 120.2 (2014): 593–598. Print.

- Raoul, Valerie et al. "Narrating the Unspeakable: Interdisciplinary Readings of Jean-Dominique Bauby's *The Diving-Bell and the Butterfly*." *Literature and Medicine* 20.2 (2001): 183–208. Web. 6 Jan. 2014.
- Raoul, Valerie et al., eds. *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*. Waterloo, Ont.: Wilfrid Laurier UP, 2007. Print.
- Radley, Alan. *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease*. Ashby-de-la-Zouch: InkerMen, 2009. Print.
- Rimmon-Kenan, Shlomith. "The Story of 'I': Illness and Narrative Identity." *Narrative* 10.1 (2002): 9–27. Web. 2 Jan. 2014.
- Rimmon-Kenan, Shlomith. "What Can Narrative Theory Learn from Illness Narratives?" *Literature and Medicine* 25.2 (2006): 241–254. Web. 15 Sept. 2013.
- Sands, Stephen A., Patricia Stanley, and Rita Charon. "Pediatric Narrative Oncology: Empathy, Build Teams, and Prevent Burnout." *The Journal of Supportive Oncology* 6.7 (2008): 307–312. Print.
- Scheper-Hughes, Nancy, and Margaret M. Lock. "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology." *Medical Anthropology Quarterly* 1.1 (1987): 6–41. Print.
- Schultz, Jane E., and Martha Stoddard Holmes. "Editors' Preface: Cancer Stories." *Literature and Medicine* 28.2 (2009): xi–xv. Print.
- Segal, Judy Z. "Cancer Experience and Its Narration: An Accidental Study." *Literature and Medicine* 30.2 (2012): 292–318. Web. 13 Dec. 2013.
- Segal, Judy. *Health and the Rhetoric of Medicine*. Carbondale: Southern Illinois UP, 2005. Print.

Seitz, Diana C. M. et al. "Life Satisfaction in Adult Survivors of Cancer during Adolescence: What Contributes to the Latter Satisfaction with Life?" *Quality of Life Research* 20.2 (2011): 225–36. Web. 2 Nov. 2013.

Shakespeare, Tom. "The Social Model of Disability." Davis 266-273.

Shapiro, Johanna et al. "Just a Spoonful of Humanities Makes the Medicine Go Down: Introducing Literature into a Family Medicine Clerkship." *Medical Education* 39.6 (2005): 605–12. Web. 17 Feb. 2014.

Shapiro, Johanna et al. "Medical Humanities and Their Discontents: Definitions, Critiques, and Implications." *Academic Medicine* 84.2 (2009): 192–8.

Shuman, Amy. *Storytelling Rights: The Uses of Oral and Written Texts by Urban Adolescents*. Cambridge: Cambridge UP, 1986. Print.

Skott, Carola. "Expressive Metaphors in Cancer Narratives." *Cancer Nursing* 25.3 (2002): 230-5.

Smith, Sidonie, and Julia Watson. *Reading Autobiography: A Guide for Interpreting Life Narratives*. 1st ed. Minneapolis: University of Minnesota, 2001. Print.

---. *Reading Autobiography: A Guide for Interpreting Life Narratives*. 2nd ed. Minneapolis: University of Minnesota, 2010. Print.

Sontag, Susan. *Illness as Metaphor*. New York: Farrar, Straus and Giroux, 1978. Print.

Spencer-Wendel, Susan, and Bret Witter. *Until I Say Good-bye: My Year of Living with Joy*. N.p.: Harper, 2013. Print.

Swain, John, and Sally French. "Towards an Affirmation Model of Disability." *Disability & Society* 15.4 (2000): 569–582. Web. 5 Feb. 2014.

Sweeney, Megan. *Reading Is My Window: Books and the Art of Reading in Women's*

- Prisons*. Chapel Hill, NC: University of North Carolina, 2010. Print.
- Sweeney, Megan. *The Story within Us: Women Prisoners Reflect on Reading*. Urbana: University of Illinois, 2012. Print.
- Takemura, Yousuke et al. "Open-Ended Questions: Are They Really Beneficial for Gathering Medical Information from Patients?" *The Tohoku Journal of Experimental Medicine* 206.2 (2005): 151–4.
- "Theme." The Oxford English Dictionary. 2nd Ed. Online.
- Thomas, Carol. *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*. New York: Palgrave Macmillan, 2007. Print.
- Tomlinson, Deborah. "Adolescents with Cancer." *Nursing in Haematological Oncology*. Ed. Maggie Grundy. Edinburgh: Baillière Tindall, 2000. Print.
- Trostle, James A. "Medical Compliance as an Ideology." *Social Science & Medicine* 27.12 (1988): 1299–1308. Print.
- University of Michigan Medical School Institutional Review Board (IRBMED), Standard Operating Procedures. N.pub. January 2013.
- Vadeboncoeur, Jennifer Andrea, and Lisa Patel Stevens, eds. *Re/constructing "the Adolescent": Sign, Symbol, and Body*. New York: Peter Lang, 2005. Print.
- Van Der Molen, B. "Relating Information-Needs to the Cancer Experience. 1. Jenny's Story: A Cancer Narrative." *European Journal of Cancer Care* 9.1 (2000): 41–47.
- Vasudevan, Lalitha. "Looking for Angels: Knowing Adolescents by Engaging with Their Multimodal Literacy Practices." *Journal of Adolescent and Adult Literacy* 50.4 (2014): 252–256. Print.

- Whyte, Fiona, and Lorraine Smith. "A Literature Review of Adolescence and Cancer." *European Journal of Cancer Care* (1997): 137-146. Print.
- Wilkins, Krista L., and Roberta L. Woodgate. "A Review of Qualitative Research on the Childhood Cancer Experience from the Perspective of Siblings: A Need to Give Them a Voice." *Journal of Pediatric Oncology Nursing* 22.6 (2005): 305–19. Web. 1 Nov. 2013.
- Williams, Gareth. "The Genesis of Chronic Illness: Narrative Re-Construction." *Sociology of Health & Illness* 6.2 (1984): 175–200.
- Wilson, James C., and Cynthia Lewiecki-Wilson. *Embodied Rhetorics: Disability in Language and Culture*. Carbondale: Southern Illinois UP, 2001. Print.
- Wiltshire, John. "Telling a Story, Writing a Narrative: Terminology in Health Care." *Nursing Inquiry* 2.2 (1995): 75–82.
- Woodgate, R. L. "Life Is Never the Same: Childhood Cancer Narratives." *European Journal of Cancer Care* 15.1 (2006): 8–18. Web. 3 Jan. 2014.
- Woodgate, Roberta and Susan McClement. "Sense of Self in Children with Cancer and in Childhood Cancer Survivors: A Critical Review." *Journal of Pediatric Oncology Nursing* 14.3 (1997): 137–55.
- Yudice, George. "Testimonio and Postmodernism." *Latin American Perspectives* 18.3 (2013): 15–31. Print.
- Zifferblatt, Steven. "Increasing Patient Compliance Through the Applied Analysis of Behavior." *Preventive Medicine* 182 (1975): 173–182. Print.

Appendices

Appendix A: Guiding Questions

“I am doing a project about what it is like for children to have cancer. I want you to tell me what it feels like to have cancer so I can tell other kids who just found out that they have cancer. I will ask you a few questions, and there will be blank pages that you can fill however you would like to respond to the question. You can write your response, draw your response, or just tell me your response. If you do not feel comfortable responding to a question, you do not have to answer it at all, and we can move on to the next question. I will be recording the session, and it will take about an hour; if at any time you do not feel comfortable, would like to take a break, or no longer want to participate in this project, we can stop the session at any time. Do you have any questions?” Verbal assent: “Would you like to participate in this research activity?”

“Tell me about yourself.”

1. Diagnosis

- What was it like to be diagnosed?
- How did you feel when you were diagnosed?
- How did you tell your friends about your diagnosis?

2. Symptoms

- What is cancer?
- What does cancer look like?
- What do you like or not like about your cancer?
- How does cancer make you feel?

3. Hospital

- Why did you come to the hospital?
- What do you like about being in the hospital?
- What don't you like about being in the hospital?
- What do you do when you are in the hospital?

4. Treatment

- What is being done to treat the cancer?
- How does treatment make you feel?
- What are some things that you like about being treated?
- What are some things that you don't like about being treated?
- How did you keep your spirits up during treatment?

5. Advice

- If cancer was a person, what would you say or do to cancer?
- What advice would you give to a child who has just been diagnosed with cancer?
- What kind of things would you want the adults in your life (doctors, nurses, parents, etc.) to know about what it's like to have cancer?

6. Reflections

- Has cancer changed your life? If so, how?
- Anything else you would like to share about your story of the cancer experience?

Appendix B: Verbal Transcript

Zack, sixteen-year-old male in remission

“Tell me about yourself.”

Uhh I like to play sports? I had cancer when I was 9 in...in third grade and I don't know, I just...I try to do well in school. I would consider myself pretty normal so...Uhh I throw shot and disc and track and I play football.

1. Diagnosis

What was it like to be diagnosed?

At the time I didn't really know what it was, so...

How did you feel when you were diagnosed?

I mean, I was sad cause I...didn't really know what was going to happen to me I guess? So, cause I was so young, I didn't really understand it completely.

How did you tell your friends about your diagnosis?

I just said that I had to go and get surgery on something cause I didn't really know exactly what it was I had so...

2. Symptoms

What is cancer?

Uhhh...a disease. Just something that happens. Can't really control it.

What does cancer look like?

It doesn't really look like anything, anybody could have it.

What do you like or not like about your cancer?

Well, I mean, I didn't like the hospital food. Nahh, it wasn't really a good experience at all (was there anything you liked?). Yeah, it just wasn't good.

How does cancer make you feel?

What do you mean by that? I mean, I felt pretty normal until I had the surgery. I mean, everything was...I felt the same, it was just that I was peeing blood, that was why I didn't...that's how they found out, I mean, other than that I was completely normal..so.

(how did you feel after surgery?)

Different. I mean, I was kinda like depressed and worried that I would get it again for a little while, and...not completely normal but I don't think about it anymore so...

3. Hospital

Why did you come to the hospital?

Umm... to get checked out? Umm cause I was peeing blood.

What do you like about being in the hospital?

Nothing. Just...I mean, everybody was feeling so bad for me, I felt, I mean I felt like I was going to be fine and everybody was just scared... I mean, I was scared, but I knew I was going to be alright. So, I just didn't like that part of it.

(Was there a way you preferred for people to respond?)

I mean, being worried I didn't mind so much, but it was just like...people crying, it was just kinda like...it made me feel bad and I couldn't really do anything about it.

What don't you like about being in the hospital?

What do you do when you are in the hospital?

Uhh... I pretty much did nothing. I couldn't really move, cause they went in through the stomach so it was hard for me to do much. So... I just kinda wait.

4. Treatment

What is being done to treat the cancer?

Uh they took out my kidney.

How does treatment make you feel?

Uh, it...I just had a pain in my stomach because they went right through 'here' to get it out so...that's...I mean, other than that, I felt fine afterwards.

What are some things that you like about being treated?

What are some things that you don't like about being treated?

How did you keep your spirits up during treatment?

I don't know, I just kinda dealt with it I didn't really...it was just something I had to go through, I didn't really think about it. Just...just try to get through it, you'll be fine in the end. Doctors know what they're doing.

5. Advice

If cancer was a person, what would you say or do to cancer?

Kill it.

What advice would you give to a child who has just been diagnosed with cancer?

Let the doctors do what they have to do. They know what they're doing, and they're going to help as best as they can.

I got it at a time when I wasn't really doing anything so it didn't really affect it... cause I was playing football in the summer, but it didn't really...it didn't affect me after that. So there isn't really a good time to have cancer, but I guess it was the best time I could've gotten it I guess.

What kind of things would you want the adults in your life (doctors, nurses, parents, etc.) to know about what it's like to have cancer?

It can happen at any time and any place you can't...it just happens, and sometimes you don't expect it. Just be ready for it when it does happen.

6. Reflections

Has cancer changed your life? If so, how?

I don't think so. I mean, I...feel the same way as anyone else would, I mean, I just have to come in and get checked out every year. But other than that, I'm fine, I just have to...be careful with staying hydrated with my kidney, other than that I'm ok.

Anything else you would like to share about your story of the cancer experience?

Nah, I think that's it.

Appendix C: Written Narrative
Lexie, fifteen-year-old female in relapse

TEENS TAKING OUT CANCER

By: Lexie C.

Devastating Diagnosis

Devastating, horrifying, and heart-breaking are some of the most common words associated with the word cancer. Although being diagnosed with cancer is a hard thing to deal with and understand, it doesn't have to be that bad especially if you have a good attitude about it. That is what I am here for; to share my personal experience and to answer the many frequently asked questions. Hopefully, this will give teens a better understanding of how this whole "cancer" thing works.

Q.) What was it like to be diagnosed?

A.) Being diagnosed was hard, all my friends and family were crushed. Unfortunately, I have been diagnosed 5 times so for me, after a while, the words "you have cancer" didn't really faze me.

Q.) How did you feel when you were diagnosed?

A.) Like I said before, hearing that I had cancer didn't really faze me. Generally, I have a pretty upbeat attitude about things. Of course I was sad, but I knew sort of what was going to happen; I faced the facts and moved on.

Q.) How did you tell your friends about your diagnosis?

A.) Telling my friends was always a challenge. It was hard explaining that I wouldn't be able to go out or join in on parties, that I would be sick and tired most of the time, that they wouldn't see me at school very much. Lucky for

me, all of my friends really understood; they tried to comfort me and told me no matter what we would still be friends.

Stupid Symptoms

Everyone's symptoms vary depending on medication and treatment plans. Some symptoms can be as little as headaches, stomach aches, soreness and fatigue. More serious stuff could be skin rashes and other skin issues, organ issues bone thinning and all kinds of other stuff, but don't let that worry you everyone is different just be prepared for what could happen.

Q.) What is cancer?

A.) Cancer can be represented in many ways. Sarcomas and Lymphomas are two common types of cancers. Within those two categories there are tons of different types of cancer, some are tumors, some are skin, some are organ or they could be like mine, blood cancer.

Q.) What does cancer look like?

A.) Cancer can be seen many different ways. Pale skin, skinny faces, bumps or rashes, bald heads, handi-cap, even amputees. Nevertheless, we are still people and that is how we should be treated.

Q.) What do you like or not like about your cancer?

A.) Well, there are many things I like and don't like about having cancer, One thing I like is all the great people I've befriended and experiences I've

gotten to see, but there are many things I have had to miss out on due to appointments or just not feeling well.

A Home at the Hospital

You will find that the hospital becomes your second home and the staff your second family. It is pretty easy to assume that you will be in and out of the hospital a lot. Medicine does funny things to your body and sometime they bring you in for a fever or other things. If you plan for the stay and bring things to keep you busy, the stays are really not that bad.

Q.) What do you like about being in the hospital/ what don't you like?

A.) I probably speak for most of the patients when I say the best part about being in the hospital is the 24/7 attention and care and upbeat nurses. What isn't the best is the below average food, the IV pumps constantly going off and the late night interruptions.

Q.) What do you do when you are in the hospital?

A.) I try to do as much as I can while I feel good, but because the medicines made me feel tired and icky and the pumps kept me up all night I didn't really feel up to doing a whole lot. I am not sure about other hospitals, but U of M offers art therapy, music therapy, a wonderful child-life program that can assist you with crafts, games or just someone to hang out with; also they have pizza and live entertainment on Thursday night for the people who are in-patient.

Tricky Treatments and Tips to Getting Through

Depending on what type of cancer or where it is in your body, treatment plans can vary greatly. In my personal experience I've had a variety of different treatments. I've had radiation, many different types of chemotherapy, and a bone marrow transplant and now we are starting a new therapy called Immunotherapy. It's pretty safe to say that I have seen almost all of it. During my long life of cancer I have learned the tricks and trades of making it through. There are some really simple things that you can do to make a crappy day a little better. (Look in the back for some fun tips and tricks)

Q.) What are some things you like about being treated/ what are some things you don't like?

A.) Well, I can't say that there is a whole lot of things I like about being treated other than the fact that it is keeping my cancer at bay. Certainly, I can tell you a lot of things I don't like. One thing I don't like is how chemo and other treatments make me feel. Sometimes they make me feel icky and tired almost all the time. The one thing I hate the most though is the time spent away from friends. You may find yourself alone at times because your friends don't ask you to hang out. My advice, don't get mad at them or blame them for not hanging out with you because that could stir up a lot of problems. Most of the time they don't know how to react, chances are they really want to be your friend still.

Q.) How did you/ do you keep your spirits up during treatment?

A.) This question is my most frequently asked question; it's like everyone wants to know my secret or something. Here is the thing, cancer sucks and we all know it so instead of wasting the little energy I have left pouting and throwing myself a pity party, why not smile and try to enjoy life a little. I find that if I keep a more positive attitude my appointments go faster, treatments feel better and in general people want to be around me more.

A Teens Advice

Throughout my journey with cancer I have experienced a lot. There were many things I wish I never knew about, but there have been many experiences that I am very grateful I have been able to take part in. If I could give anyone advice the biggest piece of advice I can give is to have a good attitude and try to live life to the best of your ability because later on you will regret all the opportunities you passed up.

Q.) What advice would you give to a teen that has just been diagnosed?

A.) My advice to any teen that has just been diagnosed is to live life like nothing is going on. Don't pass opportunities up because you don't think you can do something or are too embarrassed. Nothing about cancer is positive, but you can make the best out of the situation. For a long time I didn't want to swim in front of my friends because I couldn't wear a wig in the pool. Just recently I was at a friend's birthday party and it was a bowling party but I had a fractured foot so I didn't think I could play. My friends were so supportive; they even helped me bowl so I could join in on the fun! I would have never known how much fun either of these things would have been if I

had let silly little embarrassments get in my way. Another piece of advice is to speak up. If you don't like something or something doesn't feel right you need to say something. It is so important for you to voice your opinion because the doctors and nurses can sometimes fix things to make them more comfortable, and remember they are human too they could have made a mistake.

Q.) What kind of things do you want adults in your life to know about what it's like to have cancer?

A.) I assumed they meant adults in general when they asked this question. I want them all to know that we are just normal kids; we don't need to be talked to differently, looked at funny, asked embarrassing questions and monitored like prey every minute. This goes for family, friends, people in public and doctors.

Remember and Reflect

When reflecting back on my journey only one question is asked that's really important. It's basically two questions in one but it has such a huge impact.

Q.) Has cancer changed your life and would you change it all if you could?

A.) I am not sure I would change everything. Cancer has been a part of my life for so long, it has made me who I am and allowed me to see things in a whole different way. If I were to change anything about my cancer it would be the amount of relapses. One time through is more than anyone should have to deal with, 5 times is not something I have enjoyed.

Cancer has made me realize that life isn't easy, but you have to have faith, trust and courage; with these three things, you can accomplish anything! The

journey, as awful as it is has shown me to go for my dreams and work extra hard because I have been given the gift of life and I can't waist something so precious. Currently, I have my own non-profit organization that aids sick children and children in poverty. I am an honors student and I have a job working with young children, Yes, I still take chemo, but I try really hard to run as normal of a life as possible.

A Few Facts about Me!

Now that we have gotten through all the questions and stuff I am sure you are curious as to who wrote this. Well, my name is Lexie and I am an only child. I live at home with two dogs and cat, which I love very much. Some of my favorite hobbies are crafting, swimming, writing, spending time with friends and watching movies. A few of my favorite TV shows are Criminal Minds, Full House, George Lopez, cooking competitions and the Style Network. Normally, I am a pretty busy person; I have tutored for elementary age reading, I work at a pre-school and I run a non-profit organization. When I am not busy with any of that I try to spend time with family and friends.

Now that you have gotten to know a little bit about me and have read my experiences and thoughts, I hope that your questions and worries have been clarified. Hopefully, you enjoyed my story and are inspired to get out and live life, work for your dreams and get out of your comfort zone.

Thanks for reading!

Lexie C.

IDEAS, TIPS AND TRICKS!

Easy hospital food treats

Creamsicles in a cup:

- .1 single serving of orange sherbet (raspberry works well too)
- . 1 single serving of vanilla ice cream
 - Scoop both into cup and mix until soft, then ENJOY!

Sunday breakfast scramble (close enough)

- .Order of scrambled eggs
- .Order of link sausage or hot dog
- . 1 slice of cheese (your preference)
 - Slice sausage and mix in with eggs. Place cheese on top and microwave for 30 seconds.
 - Enjoy!

Crafts and other fun ideas!

- . Practice your skills by solving crossword puzzles and other mind games
- . Start a blog or write in a journal
- . Build a model car or paint a pot
- . Knit a scarf
- . Make make-up, hair or nail tutorials
- . Create fan pages or interest pages on facebook
- .Write a song or poem

Fun, safe websites for all age's not just teens!

- <http://www.imvu.com> (recommended for teens only)

- <http://www.howrse.com>
- <http://www.stardoll.com/en>
- <http://www.edheads.org>
- www.coolmath-games.com
- <http://pbskids.org/games/>
- <http://disneychannel.disney.com/games>
- http://www.barbie.com/activities/fun_games/#/whats-hot
- <http://www.miniclip.com/games/en>