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# A Narrative and Performative Methodology for Understanding Adolescent Cancer Stories

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A NARRATIVE AND PERFORMATIVE METHODOLOGY  
FOR UNDERSTANDING ADOLESCENT CANCER STORIES

A Dissertation

Submitted to the Graduate Faculty of  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

in

The Department of Communication Studies

by

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## ABSTRACT

The field of health communication places considerable attention on coping with cancer, typically using social scientific approaches to investigate uncertainty, information, and/or social networks. Social scientific models of coping with adolescent cancer often measure how behaviors seek to manage cancer's uncontrollability and/or uncertainty; however, how adolescents cope with cancer has been unclear. Short-term studies show adolescents typically and atypically cope. Long-term studies show a significant portion of survivors exhibit post-traumatic stress. The narrative and performative turns expose the role narratives and performatives play in shaping human subjects as meaning makers rather than merely information sharers. A narrative subject reframes cancer's uncertainty and uncontrollability to be a matter of storytelling through which patients embark on a liminal journey of illness situated in socially shared narratives. The performative turn adds to a narrative perspective by foregrounding the contingency of the body and how bodily acts (re)produce subjective identities, and where performed actions (re)materialize sociocultural meanings. From this perspective, coping with a cancer identity is a matter of the performative, through which patient bodies negotiate liminal identities. I view coping as an act of embodied apperception: a series of acts by a narrative and performative subject. What the patient says and does while telling a cancer story exposes complex narrative and performative negotiations of coping with a cancer identity. To explore coping with an adolescent cancer identity, I apply critical self-reflexive (auto)ethnography through which I first tell my cancer story. By foregrounding the narrative and performative approach, I reveal: (1) a cancer diagnosis and its narrative as language in action; (2) the uncertain and uncontrollable narrative liminality of adolescent cancer patients; and (3) narratives and their discursive structures create performed actions, narratives, and narrative identities as much as they are created by performed actions, narratives, and narrative identities. Next, I apply a narrative and

performative analytic as I critically and reflexively engage four videos of adolescents telling a “my cancer story.” The analysis of these videos maps a dramatic framework for these cancer stories through which adolescent patients embody liminality’s redress through reintegration as normative and/or embody schism through embracing a non-normal body.

## CHAPTER 1 INTRODUCTION

In the last thirty years, the National Cancer Institute (NCI) reports increased incidences of cancer in adolescent patients (NCI, 2011; Jones et al., 2013). NCI also reports increased rates in survivors of adolescent cancer. When diagnosis of adolescent cancer increases and mortality from adolescent cancer decreases, more adolescent cancer patients live through cancer. Thus, a shift from patients “coping with dying from cancer to [patients] coping and living with cancer” (Pecchioni & Sparks, 2007, p. 143) occurs. This data begs for new research exploring the adolescent cancer patient’s experience from a cancer diagnosis and its treatment. There should be a growing concern for understanding how adolescent patients cope with cancer.

Most research on coping with cancer focuses on adults and younger children, missing some of the key ways in which adolescents significantly differ from both. What research has been conducted on adolescents to date provides evidence of some important causes for concern such as smoking cigarettes (Clawson et al., 2015), not discussing cancer with peers (van der Velden & Emam, 2013), and skipping medication (Jones et al., 2013), which “can lead to medical complications and an escalating cycle of avoidant coping” (p. 2148). Avoidant—or disengagement—coping behaviors like these are maladaptive.<sup>1</sup> The patients not only seek to avoid a stressor, but also their actions place them at higher risk for illness, and adolescent cancer patients already exhibit similar unhealthy behaviors as noncancerous peers (Clawson et al., 2015; Tercyak, 2006; Tyc et al., 2006; Tyc et al., 1997). Because cancer patients and former cancer patients are at higher risk for maladaptive coping responses and higher risk for illness,

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<sup>1</sup> Though, some researchers uphold that determining the (mal)adaptiveness of any coping strategy is impossible, others like Skinner, Edge, Altman, and Sherwood (2003) have argued for an adaptive and maladaptive frame for coping.



researchers have called for preventive intervention programs targeting adolescents and former adolescent cancer patients. How adolescents cope can also “place them at risk for diminished long-term psychosocial adjustment” (Wu et al., 2009, p. 2359). Research on survivors of adolescent cancer shows a significant number of former patients exhibit Post-Traumatic Stress Symptoms (PTSS) and/or Post-Traumatic Stress Disorder (PTSD) (Rourke et al., 2007; Kwak, et al., 2013; Kazak et al., 2004). This requires further exploration into the chaotic nature of adolescent cancer patient experiences and what it means to be an adolescent cancer patient, and to have lived through adolescent cancer.

A dominant strand of social scientific research on coping with cancer tends to understand coping primarily as a matter of information sharing and/or gathering. This research tends to view coping with cancer from two theoretical frameworks: as situational or as personal. In a situational frame, coping is a transaction: a person’s behaved response to stress results from cognitive and/or emotional appraisal of a stressor (Cocchiara, 2017; Biggs, Brough, & Drummond, 2017; Folkman, 2010; Lazarus & Folkman, 1984). In a personal frame, coping is an individual experience through which a person’s behaved response to stress is dispositional and/or learned (Warr, 2017, pp. 64-65; Haan & Lykken, 2013; Folkman, 2010; (Johansen et al., 2013). When it comes to adolescents, nearly all this research neglects the important ways in which coping, for all patients, but particularly for those who are adolescent, transcends information to become a matter of self-storying, self-performing, and identity (re)formation.

Coping with cancer is clearly difficult at any age, but perhaps more difficult for adolescent patients. Adolescence is a time of heightened awareness (Elkind, 1967; 1968; Schwartz, Maynard, & Uzelac 2008), during which one’s identity is already in flux, an effect that can be both stunted and exaggerated by the flux of a cancer diagnosis. Many adolescents

tend to show concern regarding how others perceive their bodies and bodily performances (Elkind, 1967; 1968; Schwartz, Maynard, & Uzelac 2008), exposing sociocultural consequences affecting performed actions through an individual's choice, or agency (Ryan & Kuczkowski, 1994). A cancer diagnosis places a cancer label onto an adolescent's already fragile identity. The uncertainty and uncontrollability associated with a cancer label and what it means to be and become a cancer patient resides in sociocultural consequences for adolescents through a new cancer identity. Because humanistic theories and methods can provide a more complex and layered approach to coping with cancer, they provide a means to understanding coping with adolescent cancer as a matter of one's cancer identity, more than merely as a matter of processing cancer information. From this framework, sociocultural consequences associated with cancer can exist outside of one's choice and/or dispositional response. The human body is not a machine responding to stimuli, but rather a performing and narrating force that co-constitutes its identity in relationship to its sociological and physical environment.

The disruption of identity, perhaps a fact for all patients diagnosed with cancer, is especially pronounced for adolescent patients. Adolescence is a time of biological, social, and psychological development (Uba & Huang, 1999). Moreover, adolescence is a time of heightened ego (Elkind, 1967; 1968; Schwartz, Maynard, & Uzelac 2008), as identities are palpably in flux. Adolescent cancer patients not only cope with stressors related to cancer, they cope with everyday life stressors associated with being an adolescent. During adolescence, conscious awareness of one's body and bodily performances intensifies, involving an imaginary belief of how others perceive the self (Elkind, 1967). Social roles and social performances emerge during adolescence, where schools, jobs, friends, classmates, sports, clubs, and more (Uba & Huang, 1999) shape and reshape adolescent identities. Peers and peer groups "gain

importance” (p. 351) during this stage of life, but the social consequences, which result from peer interactions, heavily influence adolescent self-esteem and decision-making (Ryan & Kuczowski, 1994). Adolescent cancer patients traverse different social worlds. Each world has its own set of sociocultural conventions, rituals, and rules, which can constrain adolescent performances to conform, “represent[ing] a loss of autonomy” (p. 222). Autonomy goes hand-in-hand with agency, and a loss of one positively correlates with a loss the other.

Psychosocial research has suggested that intervention programs could benefit adolescent cancer patients’ long-term coping. Intervention programs targeting uncontrollability and uncertainty typically try to improve adaptive secondary control strategies, “including acceptance, cognitive reappraisal, and positive methods of cognitive and behavioral distraction” (Compas et al., 2014, p. 11). Coping strategies can improve maladaptive and/or avoidant acts of coping exerted by some adolescent patients. However, when coping is understood as identity formation rather than merely information seeking and adaptation, these maladaptive acts of coping can be moments when patients exert agency in their cancer stories. When adolescent patients choose to resist medical treatment, they resist a medical narrative through which medical authorities control the patient’s story. Thus, adolescent cancer patients offer us insight not only into how they adapt to the biomedical story in which they find themselves, but also into some of the ways that dominant story fails to account for the complexity of their lived experiences.

### **Why the Act of Telling a Cancer Story?**

In the humanities, both the narrative and performative turns have shifted paradigmatic frames for understanding the human subject. In a narrative frame, a subject is a narrative self-maker, narrative sense-maker, narrative meaning-maker, and narrative world-maker. A narrative paradigm makes understanding personal stories imperative. Stories are acts of telling personal experiences reflexively situated in narrative shaped realities. For example, many cancer patients

and former cancer patients chronologically tell their personal cancer stories by first describing symptoms, then the process of diagnosis, followed by experiences in treatment, and possibly completion of treatment. These personal cancer stories not only share narrative elements such as arrangement, but also other narrative elements such as metaphor, metonym, symbolism, and more. For example, Susan Sontag noted cancer stories often use military language: fighting cancer, battling cancer, beat cancer, et cetera. Thus, in the act of telling, the storyteller shares her or his cancer experiences through narrative elements already socially and culturally shared. The act of telling a cancer story then can contribute to reshaping culture through the usage of common shared narrative elements. In addition, the act of telling a cancer story can also resist those shared narrative elements by storying cancer differently. In a performative frame, a human subject is a performative self-maker, performative sense-maker, performative meaning-maker, and performative world-maker. A performative frame makes it imperative to understand the performing body, because bodily actions reflexively (re)produce, and are (re)produced by, sociocultural texts including narratives and the language used to tell one's story.

The relationship between stories and illness is not new in either medical or academic practice. Charon, Executive Director of Narrative Medicine at Columbia University Medical Center, for example, puts narrative medicine into medical education and medical practice. She claims narratives inflect every part of medicine, and "Narrative Medicine," can "forge the intersubjective connection to sick people, and to fulfill the ethical duties incurred by hearing the stories of illness" (Rudnytsky & Charon, 2008, p. 25). Narrative medicine champions physicians taking a role wherein they deeply listen to patients' biographical stories, stories of illness, including stories from friends and family members.

The narrative turn resurfaces interest in a narrative paradigm (Fisher, 1984; Ricoeur, 1985; Bruner, 1991), and its insights into how privileged narratives in public discourses share conventional structures (e.g. plot, metaphor, metonyms, binaries). The narrative paradigm asserts the human subject is born into a narratively constructed reality, one must be and become in a sociocultural system of shared narratives (Ricoeur, 1985). The human subject must make sense and meaning through these shared narrative elements. Telling a cancer story can expose how a patient sees herself or himself in the story of cancer. In telling a cancer story, individuals recall and arrange fragments of cancer experiences in such a way that storytellers contextualize how they manage cancer as well as their movement through a cancer story. These stories must situate in and/or against dominant narratives circulating in social discourses about cancer and illness.

Research on personal cancer stories can expose shared narrative elements inflecting individual cancer stories. These stories can also illuminate how the performance of storytelling becomes an embodiment of narrative apperception: the negotiation of new narrative experiences through the lens of one's ongoing narrative self. Thus, in the telling of a cancer story, the storyteller describes and performs her or his role with cancer but also how cancer permeates other everyday roles (e.g., school, friends, family) and how everyday roles permeate cancer. The embodied telling of a cancer story can constitute the storyteller's narrative identity as a cancer patient. Because adolescents have a heightened awareness of identity, theoretical and methodological approaches focusing on the performing body and its identity as reflexively tethered to narrative discourses add critical insight to, and broaden the field of, coping with adolescent cancer. In this theoretical frame, coping is more than a behaved response determined by either a person's cognitive/emotional appraisal or an individual's dispositional/personality traits; coping becomes enmeshed in one's narrative identity, or the role one takes in the story of

cancer. Coping with cancer is a matter of personal narrative and identity. Analyzing narrative elements and the embodiment of telling a personal cancer story may reveal how these adolescents cope with the uncontrollability and uncertainty involved with cancer experiences and the active or passive roles patients can play in co-constructing their cancer identities.

### **Preview of Chapters**

In Chapter 2, I first review predominant coping literature in social science and biomedical approaches to stress to expose the harmful effects stress has on the physical body. From a biomedical framework, physical restitution of the patient is the goal, and physicians treat stress to restore and protect the body. Next, I review research in two common psychological approaches to stress: situational and personal models for coping. Situational models base research on a biopsychosocial subject, investigating a subject's cognitive and/or emotional appraisal of a stressor. Personal models use a psychosocial or biopsychosocial subject, grounded in ego psychology. In this framework, coping responses situate in behaviors tied to personal disposition, personality traits, and/or development. Then I review common situational and personal approaches to coping with cancer in social scientific research. This research typically offers three frameworks for coping with stressors related to cancer: responsibility for cancer; uncontrollability of cancer; and uncertainties associated with cancer. Finally, I review approaches by the field of health communication. Health communication often uses transactional models to examine coping within three overlapping frameworks: uncertainty, information, and support. I end the chapter by reviewing humanistic approaches in health communication, which explore the role of narratives and storytelling in the act of coping with illness.

In Chapter 3, I apply a humanistic approach to foreground the import of stories and performance. I first discuss ethnography to situate my method of performative writing in ethnographic scholarship. Next, I give a brief history of ethnography and problems associated

with ethnographers' early application of the method. I do this to foreground the contemporary ethical concerns I take in employing ethnography as a methodological approach. Then, I detail critical and self-reflexive (auto) ethnography to situate performative writing as an approach that accounts for more than my subjectivity; it is an approach that seeks to expose power embedded in sociocultural systems of shared symbolic meanings.

In Chapter 4, I employ a critical and self-reflexive performative writing to detail a narrative and a performative model for how I cope/coped with my cancer identity. Throughout the chapter I offer fragments of my experiences as an adolescent cancer patient, along with my present coping experiences when engaging research on coping with adolescent cancer. I review narrative paradigm, narrative identity, and performativity to situate my acts of coping as performative negotiations of my narrative identity. When combined, these theories can function as a model to expose: (1) a cancer diagnosis and its narratives as language in action; (2) the uncertain and uncontrollable narrative liminality of adolescent cancer patients; and (3) narratives and their discursive structures create performed actions, narratives, and narrative identities as much as they are created by performed actions, narratives, and narrative identities. This model provides a lens to view the complexity of coping with a cancer identity as well as the import of one's personal cancer story of cancer.

In Chapter 5, I apply the narrative and performative model I fashion in Chapter 4 to analyze four videos of teenagers telling a "My Cancer Story." I first conduct a narrative analysis through Frank's (1995) illness narratives and their underlying three stages: pre-liminal, liminal, and post-liminal. I directly look at the narrative arrangement in each story, the language used in telling the story (e.g. metaphor, temporality, active/passive construction), and the storytellers' embodied telling of the story. This analysis offers an understanding of the passive and active

ways in which patients cope with the uncontrollability of cancer through the aesthetic act of storytelling. I summarize the narrative analysis by adding the framework of Turner's (1982; 1967) social drama, which better describes the arrangement and complexity of these cancer stories by offering four stages wherein liminality is the stage of redress through which reintegration and/or schism results. The presentation of the redressed-self foregrounds the body and bodily performance as complicit in the act of storytelling, in which performers employ normative or resistant performatives to cope with their cancer bodies. Performativity<sup>2</sup> furthers the theoretical framework for a narrative approach by adding the complexity of the body, bodily actions, and identity formation (Butler, 1988) through which the performative act of storytelling constitutes these adolescent storyteller's cancer identity, an identity bound to the performance of storytelling, the story, the self, the other, the society and culture. The personal cancer story is socially situated in narratives of cancer along with performative aspects involved with having cancer can open possibilities for new creative aesthetic coping strategies.

In Chapter 6, I conclude the dissertation through a brief summarization that speaks back to adolescents coping with cancer and why I applied a narrative and performative approach to explore adolescents storying cancer. I detail the findings from the narrative and performative analytic through which I expose coping with a cancer identity, an identity tethered to one's personal narrative, and liminal performances of redress. From the narrative stage of redress, the liminal self can (re)integrate in the social norm and/or schism as an outsider. Next, I look at the

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<sup>2</sup> Performativity has many branches extending into various disciplines (e.g. performance studies, linguistics, anthropology, gender studies, et cetera), which root in Austin's (1962) concept of the performative act where 'a saying of something is a doing of something.' Here I draw from more contemporary views on the performative, where in the act of doing something and/or saying something constitutes one's identity, an identity socially and historically situated in sociocultural meaning. I will further address performativity in chapters four and five.



implications a narrative and performative analytic has for research in coping with cancer in the field of health communication and performance studies and outline some future directions for research. For health communication, the act of storytelling can function as a site for the analysis of coping with cancer's uncertainty and uncontrollability. In addition, I offer coping with a cancer identity beyond the measurement of identity through scales of self-reliance and self-efficacy. Narrative scholarship can function as a bridge between health communication and performance studies. A performative and narrative analytic has several implications for health communication and coping with cancer: coping with a cancer identity is a performative act and can supplement existing coping research; the performance of telling a personal narrative of cancer is an act of coping, an aesthetic strategy to deal with trauma; and, the possibilities for staging personal narratives of cancer.

## **CHAPTER 2 STRESS, COPING, CANCER, HEALTH COMMUNICATION, AND NARRATIVES**

An academic search on coping with cancer can result in several thousand journal articles, most of which employ a social scientific approach to research. Social scientific scholars extensively investigate coping with stress, many taking a quantitative empirical approach to their research. This approach has provided important information; however, these approaches do not account for some of the most important aspects of coping. Subsequent research has taken a more qualitative approach to coping which offers further clarification of how humans cope with cancer and other stressors, yet even this research seems to presume a relatively static human subject that is coping with stress. Thus, these approaches miss the unique difficulties of coping that occur when an existential threat, such as a cancer diagnosis during adolescence, throws one's identity into question.

In this chapter, I review literature to articulate the importance of this study's approach to coping with cancer. I review coping research to show the ways in which coping with stress have evolved, to give my reader a sense of the most common language used in coping research, to expose limitations of pervasive social scientific approaches to coping research, to discuss the narrative turn and illness narratives in cancer stories, and to demonstrate the need for a performance paradigm (Pelias & Van Oosting, 1987) to expand a narrative approach.

I first review scientific approaches to stress and physical health. Stress is not only difficult to cope with, but also has harmful physical effects on the body and can exacerbate illness. The impact stress has on physical health warrants the seriousness of cancer patients and former cancer patients coping with stress associated with cancer. Second, I review common approaches to coping with stress in psychology. Psychology investigates coping through the

ways in which individuals manage stress, often naming and categorizing coping strategies. This focus has led to a better understanding of the complexities of how patients cope but does not account for the fluid identity that emerges in coping with an existential threat like cancer. Third, I briefly review common approaches to coping with stress specifically associated with cancer for all patients and adolescent patients in particular. These approaches view coping as the strategic management of cancer's uncertainty and/or uncontrollability; however, they pay less attention to how and why uncertainty and/or uncontrollability surface through a rapidly changing identity. Fourth, I review research on coping with cancer from the field of health communication. Social scientific approaches in health communication place a great deal of attention on coping with cancer through the lenses of uncertainty, information, and support. These lenses expose the complicated role communication plays in cancer. Health communication continues to privilege social scientific approaches to coping with cancer, hindering the needed exposure of humanistic approaches in which theories of identity contribute new insight. I end the chapter by reviewing a smaller but growing body of research in health communication that explores illness stories. Illness stories expose how coping with uncertainty and uncontrollability is a matter of one's story and, thus, one's identity. I further make the case that the performing body supplements this narrative approach to coping with cancer through an understanding of the body's contingent relationship between and among performance, stories, and identity.

### **Stress on Physical Health**

Physiological sciences initially held domain over research on stress and health. This roots in Cannon's (1915) work on the sympathetic nervous system and "the emergency response" (Cooper & Quick, 2017, p. 1). The emergency response is the body's physiological response to stress and the role of hormones such as cortisol and adrenaline. The term "emergency response"

later evolved into the terms: flight-or-fight response, stress response, and hyper arousal. Drawing from Cannon's work on stress, Selye's (1976) work investigates stress and the endocrine system, "connect[ing] stress to an array of diseases of adaptation" (Cooper & Quick, 2017, p. 1). Selye's research on the body's hormonal response "directly or indirectly linked [stress] to seven of the top ten leading causes of death in the United States, United Kingdom, and all developed nations" (p. 1) such as heart disease, cancer, stroke, injuries, suicide/homicide, chronic liver disease, emphysema [and] chronic bronchitis. More recent research suggests stress links to morbidity, exacerbates existing illness, and increases the likelihood for comorbidities. Chronic stress can increase inflammation. Inflammation plays a part in many major diseases such as heart disease, diabetes, arthritis, asthma, and cancer (Slavich and Irwin, 2014; Carr & Sosa, 2013). In this frame, stress biochemically affects the body's system, causing biochemical responses within the body that negatively affect personal health.

Medical treatment of stress exposes a perspective of patients as subjects in a "biomedical model."<sup>3</sup> The "biomedical model focuses on the pathophysiology of a patient's illness through evidence-based scientific inquiry" (Dean, 2017, p. 61). The fundamental goal of a biomedical approach is the diagnosis of bodily abnormalities through which well-reasoned treatment intends to restore a body back to health. In this model, a patient is an object and a medical authority (physician, nurse, diagnostician, et cetera) is the subject. For example, biomedicine is a common (biomedical) approach to stress in which physicians prescribe medicine to treat a patient's stress and to restore a patient back to normal. Biomedical models are important to stress research; they have shown the harmful effect stress has on physical health, centering the need for more research

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<sup>3</sup> I do not review approaches within biomedical models, such as biomedicine, bio-surgical, or bioengineering because they apply less to research on coping with stress.

on coping with stress. Despite the import of a biomedical framework, medical treatment of stress can miss the ways in which coping is more than just a patient-object receiving medicine from a doctor-subject.

### **Psychology and Stress**

Since the 1960s and 1970s, the domain over stress fell under psychological sciences with Lazarus's transactional model (1966). His transactional model emphasizes coping as a reactive process to a situational stressor. Transactional models are situation-focused, and sometimes referred to as situational models. These models remain pervasive in psychological research, and many researchers continue to use situational models to investigate the management of stress. The concept of an ego approach to coping with stress also grew in the 1970s. In this view, coping responses to stressful situations are dispositional and individual personality traits play a role in how a person will cope. Today, a good portion of research on coping with stress integrates complexities of the person in the situation, wherein earlier approaches had focused on either the situation or the person. Still, this research leaves out the ways in which some situations can throw one's very personhood and social self into question. That is, how patients must cope with stress associated with the uncertainty and uncontrollability of a cancer identity.

### **Situational Coping**

Lazarus (1966) had initially viewed coping with stress as a transactional process made "between the person and the environment, and appraisal of a stressor [was] a feature of the coping process" (Frydenberg, 2014, p. 83; Frydenberg, 2000; Lazarus, 1966). This model focuses on stress as an individual's reaction to an external stressor. Lazarus and Folkman (1984) have evolved the transactional model to view coping as how one "chang[es] cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised [and

reappraised] as taxing or exceeding the resources of the person” (p. 141). In this concept, the process of appraisal is twofold: primary appraisal<sup>4</sup> and secondary appraisal.<sup>5</sup> Transactional models have offered major contributions to research on coping with stress, frequently applying three coping responses to situational stressors: problem-focused,<sup>6</sup> emotion-focused,<sup>7</sup> and meaning-focused<sup>8</sup> (Biggs, Brough, & Drummond, 2017; Folkman, 2010; Lazarus & Folkman, 1984; Folkman, 2010). Early problem-focused and emotion-focused research predominantly relied on self-report, wherein questionnaires use a single scale for emotion-focused coping and a single scale for problem-focused coping (Folkman, 2010). Contemporary research using situational models often employ various scales and yet still privilege appraisal of the situational context when a person copes with stress. Appraisal foregrounds a human subject who exerts

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<sup>4</sup> Primary appraisal is a person’s cognitive interpretation of a stressor or stressors as threatening/unthreatening, positive/negative, and challenging/impossible (Biggs, Brough, Drummond, 2017; Cohen 1984).

<sup>5</sup> Secondary appraisal follows a person’s interpretation of a stressor, where a person now appraises controllability of the stressor through one’s available resources to respond to the stressor.

<sup>6</sup> Problem-focused coping strategies intend to reduce and/or to remove a stressor, or the degree of demand a stressor places on a person. Lazarus and Folkman (1984) suggested three types of problem-focused coping strategies: seeking control, information seeking, and evaluating a stressor as either positive or negative.

<sup>7</sup> Emotion-focused coping strategies intend to regulate personal feelings related to a stressor and/or to prevent emotional problems resulting from a stressor. Lazarus and Folkman (1984) initially suggested five emotion-focused coping strategies: discounting or avoidance of a stressor; accepting responsibility; employing self-control or self-restraint; seeking support; and positive reappraisal.

<sup>8</sup> Meaning-focused coping strategies, through reappraisal of a stressor, help with chronic “overwhelmingly aversive and uncontrollable” (Biggs, Brough, & Drummond, 2017, p. 357) stress. These strategies result when a person modifies existing values, beliefs, and/or goals to add new resources to manage cognitive and/or emotional distress.

agency and can make choices on how to cope, whereas a focus on the person rather than the situation complicates the view of coping as a transaction through a subject's appraisal.

### **Personal Coping**

Personal coping research approaches are often “psychoanalytic” (Johansen et al., 2017, p. 130) and stem from earlier research in ego psychology (Folkman, 2010; Vaillant, 1977; Miller, 1987). Personal “feelings are partly a function of several comparative judgments, concerned with where one has been, where one now might be instead, and how the future might develop” (Warr, p. 65). Like transactional models, ego psychology suggests a biopsychosocial subject, wherein one's ego psychically negotiates biological and social forces. Personal coping research seeks to understand personal disposition, personality traits, ego, defense mechanisms, self-efficacy, self-esteem, and emotion in one's “way of attending to and thinking about particular situations as they are experienced.” (Warr, 2017, pp. 64-65; Haan & Lykken, 2013; Folkman, 2010). In this model, coping is a response to stress followed by a “behavior and lastly, a loss of ego function or fragmentation” (Johansen et al., 2013, p. 130). Still, dominant psychological approaches focusing on these personal aspects of identity fail to address the formation of identity through cancer experiences. Coping is not simply a loss or fragmentation of ego, coping is a matter of picking up those fragmented pieces and creatively (re)arranging them, thus (re)constructing one's cancer identity through the performative act of telling a personal cancer story.<sup>9</sup>

### **Situational Coping and Personal Coping**

Other research draws from Lazarus and Folkman's (1984) more dynamic transactional model to investigate the person in the situation. This research includes various temporal

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<sup>9</sup> In the last section of this chapter, I discuss the import of stories in health. In chapters four and five I go into more detail about the relationship between storytelling, performance, and identity.

dimensions of one's past, present, and future experiences in problem-focused, emotional-focused, and meaning-focused coping strategies, especially as they relate to personality, ego, emotional intelligence, self-esteem, self-efficacy, resilience, and personal stratification in gender, age, socioeconomics, and other demographic information (Johansen et al., 2017; Folkman, 2010; Matthews, Zeidner, & Roberts, 2017; War, 2017). However, a "completely integrated model makes it difficult to distinguish various parts of each problem and measurement becomes a very complex matter" (Johansen et al., 2017, p. 130). Moreover, an integrated model does not account for the fragmented and dis-integrated aspects of being and becoming a cancer patient. Problem-focused, emotion-focused, and meaning-focused coping is always and already a performative action and bound to an individual's narrative identity. Coping with cancer should not only be a matter of asking: "How will I solve this problem?" "How will I deal with these feelings?" "How can I find meaning from having cancer?" Coping with cancer should also be a matter of asking: "Now that I have cancer, who am I?" and "What social value do I see myself having because of cancer?" "What does it mean to become and be a teenage cancer patient?"

### **Coping with Cancer**

Cancer is considered as a chronic stressor event that influences the patient's life . . . [a] cancer diagnosis often is accompanied with distress, such as unwanted intrusive thoughts about cancer for patients and it may lead to emotional reactions and psychological challenges, such as anxiety, hopelessness and despair, fear of dying, sense of aloneness, and sexual and body-image problems (Mehrabi, 2015, p. 1576).

Coping with stress associated with cancer is an important field of academic research. Situational and personal models of coping with stress separate early research on coping with cancer. Situational models are transactional and typically focus on an individual's cognitive and/or emotional appraisal of situational factors. Much of situational-focused and/or personal-focused approaches to research on coping with cancer explores one or more of the following



situational meaning structures: “responsibility for illness;” “uncontrollability of the situation;” and, “uncertainty of disease outcome” (Last & Grootenhuis, 2012). Responsibility for illness receives less scholarly attention in research on adolescents coping with cancer because adolescent patients tend not to feel responsible for developing cancer (e.g. whereas an adult smoker who develops lung cancer might cope with the responsibility for his or her disease). Still, for adolescents, uncertainty and uncontrollability are significant “sources of stress associated with increased emotional distress, including symptoms of anxiety and depression” (Compas et al., 2014, p. 2). Scholars who research situational coping from cancer often measure and categorize how a patient’s actions seek to gain control and/or to reduce or manage uncertainty experienced from the disease and/or its treatment. Control and uncertainty relate in many ways, and both root in Lazarus and Folkman’s (1984) transactional approaches. I briefly unpack uncontrollability and uncertainty to show how social scientific approaches to research limit other aspects of coping with cancer’s uncertainty and uncontrollability. The rapidly shifting identity resulting from a cancer diagnosis creates a narrative uncontrollability and a narrative uncertainty that is near absent in coping research.

### **(Un)Controllability**

(Un)Controllability of cancer is a complex stressor for patients, yet situational and/or personal models of coping do not account for how the perlocutionary<sup>10</sup> effect of a cancer diagnosis involves (losing) control of one’s personal narrative—one’s identity. In transactional models, primary appraisal, or “determination of the controllability of the situation determines

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<sup>10</sup> In Austin’s (1962) concept of speech act theory, the perlocutionary act is the effect the speaker’s utterance has on the receiver. Thus, a perlocutionary act results from the forces underlying the speaker’s intended and unintended meaning in the utterance. I detail more about speech act theory in chapters four and five.

whether individuals feel secure or confident” (Last & Grootenhuis, 2012, p. 94). Classifications for adolescents coping with cancer’s (un)controllability continue to investigate primary control, secondary control, and/or disengagement/avoidant (Rothbaum, Weisz, & Snyder, 1982):

Primary control coping includes strategies intended to directly change the source of stress (e.g., problem solving) or one’s emotional reactions to the stressor (e.g., emotional expression and emotional modulation). Secondary control coping encompasses efforts to adapt to stress (e.g., cognitive reappraisal, positive thinking, acceptance). Finally, disengagement coping includes efforts to orient away from the source of stress or one’s reactions to it (e.g., avoidance, denial, wishful thinking) (Compas et al., 2014, p. 2).

Primary and secondary control coping strategies are transactional and integrate problem-focused, emotion-focused, and meaning-focused coping strategies. Primary control strategies try to gain control over the stressor “by bringing the environment into line with [patient] wishes (e.g. seeking treatment, changing one’s own and other people’s behavior)” (Last & Grootenhuis, 2012, p. 95). Secondary control coping strategies try to gain control over the stressor “by [patients’] bringing themselves into line with environmental forces (e.g., seeking explanations and changing expectations or attitudes.” (p. 95). Rothbaum, Weisz, and Snyder (1982) articulate a cognitive and an emotional approach for control coping strategies by pediatric<sup>11</sup> patients and/or their parents. This approach explicates four types of control strategies that “well describe the frequently occurring reactions of children with cancer” (Last & Grootenhuis, 2012, p. 95):

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<sup>11</sup> Adolescent patients typically fall under the purview of pediatrics and pediatric hospitals.

vicarious control,<sup>12</sup> illusory control,<sup>13</sup> interpretative control,<sup>14</sup> and predictive control.<sup>15</sup> When adolescents tell a cancer story, storytellers depict various ways in which they use coping strategies to control their cancer story. My former adolescent cancer story and the cancer stories I analyze in Chapter 5 open a dimension of (un)controllability in the narration and embodiment of the story. Still, coping for an adolescent managing cancer is more than simply bringing a sense of control to one's life; it is also to be uncontrollable; to live in uncontrollability; to be an identity maker and to have a liminal—uncontrollable and uncertain—identity. I will demonstrate this further throughout chapters four and five.

### **Uncertainty**

Uncertainty is a significant source of stress for cancer patients. Many scholars have investigated and continue to investigate coping with uncertainty through measuring how patients reduce and/or manage unknown information related to the illness and/or its treatment. Lazarus and Folkman (1984) noted information seeking as a problem-focused and emotion-focused

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<sup>12</sup> Vicarious primary strategies occur when a patient attempts to “manipulate powerful others” (Last & Grootenhuis, 2012, p. 96). In secondary vicarious control strategies, a patient “attempts to associate with [physicians, nurses, or medical staff]” (Last & Grootenhuis, 2012, p. 96).

<sup>13</sup> Illusory control primary coping strategies surface when a patient tries “to influence chance-determined outcomes” (Last & Grootenhuis, 2012, p. 96). Secondary illusory control coping strategies occur when a patient relinquishes control to fate such as “praying, wishful thinking, or self-encouraging statements.” A patient may rely on God.

<sup>14</sup> Interpretative control primary strategies generally occur after diagnosis and involve a degree of information seeking as well as comprehending information related to cancer and its treatment. Secondary interpretative control strategies attempt to seek “meaning in the cancer experience” (p. 97), which is a meaning-focused coping strategy.

<sup>15</sup> Primary predictive control strategies “include gaining knowledge about the expected course of the disease, of the treatment schedule, and the side effects of treatment . . . that can contribute to prediction and can satisfy the need to know what to expect” (Last & Grootenhuis, 2012, p. 96). Secondary predictive control strategies intend “to predict events to avoid disappointment.”

coping strategy. For scholars using transactional approaches, uncertainty related to cancer can situate in various stressors associated with cancer such as patient futurities (e.g., reproduction abilities, permanent effects on the body, possibility of death), cancer information and patients' comprehension of its meaning (e.g., health literacy, health numeracy, education) (Rodriguez et al., 2012; Compas et al., 2014). When an adolescent patient tells a cancer story, narratives expose how uncertainty is a matter of identity. To live with cancer, particularly as an adolescent, is to live in uncertainty and uncontrollability—not to conquer them. To be a cancer patient is to have a liminal identity, not simply to have a set of symptoms. Because uncertainty and information involve communicative sharing, the field of health communication has placed considerable attention on uncertainty.

### **Health Communication and Coping with Cancer**

The field of health communication has a broad purview, extending beyond its sub-disciplinary practice by scholars and students in the discipline of communication studies. Health communication scholarship has “applied multidisciplinary, interdisciplinary, and transdisciplinary approaches” (Parrott, R. & Kreuter, M.W., 2011, p. 3). Much of this scholarship situates among and between sociology, psychology, communication, biology, and medicine (Parrott, R. & Kreuter, M.W., 2011). This breadth of scholarship has led to various scholarly definitions of, understandings of, and approaches to, health communication. Many scholars explore the field by

supporting, and empowering individuals, communities, health care professionals, policy makers, or special groups to adopt and sustain a behavior or a social, organizational, and policy change that will ultimately improve individual, community, and public health. (Schiavo, R., 2014, p. 3).

Kreps (2011), a leading figure in health communication, argues the field has the potential to be a ‘big science.’ Kreps supports a pragmatic approach to health communication in which

research seeks “valid, reliable, and generalizable data for guiding solutions to the problems that healthcare consumers and providers face” (p. 597). Thus, Kreps believes research data should be translatable to better health practices and health outcomes. Kreps (2002) critiqued the field for studying small and/or unrepresentative sample sizes, employing poor research questions, using unrepresentative/inaccurate measurements/tools, and/or “unrealistic conditions” (Kreps, 2011, p. 597). When Kreps called for health communication scholarship to ‘go the extra mile’ by employing rigorous methods and ambitious far-reaching research designs, he called for improving the field’s real-world application. Kreps included research approaches triangulating quantitative and qualitative data, stating research should “demystify the many complexities of healthcare and health promotion” (p. 596) in which the telos seeks to improve health practices and/or health outcomes. Health communication’s approach to coping with cancer has often been pragmatic. This research looks to improve the wellbeing of cancer patients by improving health outcomes through focusing on three areas: uncertainty, information, and support. A good portion of this research is empirical, employing quantitative approaches. A smaller but growing body of qualitative research in health communication explores illness narratives. These narratives expose passive and/or active coping with the (un)controllability of an individual’s cancer story.

### **Uncertainty, Information, and Support**

Uncertainty, information, and support, in the field of health communication, constitute a good portion of research on coping with cancer. This is especially true in the *Journal of Health Communication* and *Health Communication*. As I have illustrated earlier, patients recently diagnosed with cancer face a high degree of uncertainty and uncontrollability. A cancer patient’s uncertain and uncontrollable present and future is an immediate implication of a cancer diagnosis. When considering the components of transactional coping, a patient’s primary and

secondary appraisal of uncertainties associated with cancer can lead patients to employ problem-focused, emotion-focused, and/or meaning-focused coping strategies such as reducing/managing unknown information about cancer and/or seeking support to manage cancer's overwhelming feelings. Uncertainty management, information seeking, and support seeking are transactional coping strategies, relying partly on cognitive and/or emotional appraisal as a function of the coping process. These approaches presume that the underlying human subject is stable through passive and active seeking behaviors. Viewing the coping-subject in this way does not account for the fluidity of identity and its relationship to uncertainty and uncontrollability.

### **Uncertainty and Information**

Information has an enormous influence on health-related lifestyle factors, early detection and diagnosis, coping with disease, managing symptoms, engaging in active medical decision making, understanding different treatment options, and ultimately, facing end-of-life challenges (Galarce, Ramanadhan, & Viswanath, 2011, p. 167).

Information related to illness extends to many areas yet approaches to coping with information in the field of health communication often view the human subject as active and/or passive in her or his cognitive and/or emotional appraisal of a stressor's uncertainty, wherein coping surfaces in the person's subsequent actions to reduce or manage uncertainty. As information technologies continue to become more available, information seeking as coping with cancer's uncertainty extends into various areas of research in health communication. (Galarce, Ramanadhan, & Viswanath, 2011; Shyam Sundar, Rice, Kim, Sciamanna, 2011). Information seeking as coping with uncertainty draws from Miller's (1995) coping styles (Galarce, Ramanadhan, & Viswanath, 2011). These coping styles look at a range of information seeking

behaviors from monitors<sup>16</sup> to blunters<sup>17</sup> (Galarce, Ramanadhan, & Viswanath, 2011; Walsh et al., 2010; Eheman et al., 2009; also see Miller, 1995). Research on information seeking behaviors of cancer patients provides invaluable data on the sources of information patients seek to manage uncertainty (Eheman et al., 2009); patients' demographic and information seeking behaviors (Smith, Wolfe, & von Wagner, 2010); the influence information and its sources have on patient decisions for treatment (Walsh et al., 2010; Eheman et al., 2009); and, the impact information seeking has on patient efficacy (Niederdeppe, 2008; Kealey & Berkman, 2010; Baurele et al., 2006). Information seeking is present-focused and future-focused, offering patients a degree of predictive controllability. However, when a patient appraises cancer's uncertain information as likely to reveal negative outcomes such as loss of limb, disfigurement, or death, then avoiding cancer's unknown information can be an emotional-focused coping strategy. Coping with cancer's uncertain information is important but coping with cancer's uncertainty and uncontrollability extends further than information and information-seeking. In fact, information seeking to reduce and/or to manage uncertainty minimizes the role communication plays by viewing coping as transactional. Uncertainty and uncontrollability are also a matter of a patient's emerging identity: becoming a cancer patient.

### **Uncertainty, Information, and Support.**

Uncertainty is a significant component of the illness experience, as individuals struggle to make sense of the physical, social, emotional, and psychological signs associated with

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<sup>16</sup> Monitors are patients who “actively search for information about their illness and are alert to symptoms, possible side effects of treatment and . . . desire a large quantity of information” (Eheman et al., 2009, p. 488). Monitors tend to be unhappy with information provided by medical staff and instead often believe outside sources.

<sup>17</sup> Blunters are patients who exhibit extreme passive information seeking behavior. Blunting occurs when a patient intentionally avoids cancer information. Avoidance of cancer information becomes an emotional-focused coping strategy. (Galarce, Ramanadhan, & Viswanath, 2011, p. 171; Eheman et al., 2009; also see Miller, 1995).

disease. While some have argued that social support acts to reduce uncertainty, other scholars assert that it is more likely that support can help us to manage, rather than reduce uncertainty (Berlin Ray & Apker, 2011, p. 434).

The relationship between uncertainty, information, and support is also transactional. For Lazarus and Folkman (1984), support is an emotion-focused coping strategy. In transactional models, emotion-focused coping strategies result from a person's appraisal of a situational stressor as uncontrollable and/or unmanageable. In this framework, a person seeks support to regulate stress related to overwhelming feelings. For example, an acute cancer diagnosis, such as stage IV colorectal cancer, can leave a patient feeling overwhelmed and powerless over the illness, influencing a patient's psychological and emotional wellbeing. From this example, when a cancer patient seeks supportive interaction from his or her social network, then the act of seeking support is transactional and a coping strategy. Social networks can provide a patient with supportive interactions through mutual acts of sharing thoughts, information, and experiences. Support networks assist in reducing and managing patient uncertainties, and influences patient interpretations of health information, decisions for treatment, attitudes toward health, beliefs of health, and perceptions of health (Berlin Ray & Apker, 2011; Goldsmith & Albrecht, 2011).

Health communication research on coping with cancer recognizes and emphasizes how supportive conversations in social networks can mitigate stress and improve a person's physical and mental health. Supportive communication and support networks expose the co-construction of support through communicative interactions in social networks (Berlin Ray & Apker, 2011). Health communication separates supportive communication and support networks as two mutually inclusive constructs (Goldsmith & Albrecht, 2011). Supportive interactions intend to communicate "reassurance, validation, and acceptance, offer perspective shifts on cause-effect contingencies; enhance another's training or skills; coordinate sharing resources and assistance;



enable disclosure of thoughts and emotions” (Goldman & Albrecht, 2011, p. 336). The field of health communication investigates the complex and layered nuances of enacted supportive communication and positive health outcomes through several styles of support: informational support,<sup>18</sup> emotional support,<sup>19</sup> appraisal support,<sup>20</sup> and tangible support.<sup>21</sup> Goldsmith and Albrecht (2011) note supportive communication can be both beneficial and harmful depending on other members of the network and the quality of information and interaction one receives in the supportive transaction.

Health communication research investigates structures of, and density in, support networks. Members in a person’s social network share sociodemographic and psychographic similarities and/or dissimilarities. Social networks include the roles and relationships of members, the perceived number of members, the frequency of using members for support, and the strength of ties one feels with members as well as ties between and among members (Goldman & Albrecht, 2011; Berlin Ray & Apker, 2011). Support networks uncover how family, friends, spouses, partners, neighbors, coworkers, peers, and special groups influence a person’s health beliefs, health attitudes, and interpretation of health information. A patient’s perceived immediacy with members in one’s social network can increase trust, influencing decisions for treatment and health outcomes.

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<sup>18</sup> Informational support gives advice or shares information (Goldman & Albrecht, 2011, p. 337).

<sup>19</sup> Emotional support is “expressing caring and acceptance” (Goldman & Albrecht, 2011, p. 337).

<sup>20</sup> Appraisal support helps interpret an event or assesses options for coping strategies (Goldman & Albrecht, 2011p. 337).

<sup>21</sup> Tangible support provides resources or assists in tasks (Goldman & Albrecht, 2011p. 337).

Support networks and supportive communication are mutually inclusive. Goldsmith and Albrecht (2011) detail four types of transactions linking support networks to enacted supportive communication: feedback and social control,<sup>22</sup> health information and seeking care,<sup>23</sup> assistance with health behaviors and healthcare,<sup>24</sup> and helping cope with stress.<sup>25</sup> Support networks and enacted support are imperative to coping with stress and health outcomes. Uncertainty, information, and support overlap in various ways in the relationship between a person's support network and the enacted supportive transaction, but, again, the focus here situates coping through support as a transaction. Moreover, a focus on support ties directly to information and/or uncertainty, rather than uncontrollability. Cancer patients do not merely need support; they need new models to help relate to people as their emerging identities place them into a social role with different social meaning and thus different social value.

The breadth of coping research, though vast, exposes various complex layers in which stress and reactions to stress permeate our daily lives through experience, thoughts, language, and action. The biochemical impact stress has on the body and the relation between stress and illness perpetuates a continued need for research exposing layers in coping with stress. In this subsection I have shown some of the layers social scientific approaches to coping with cancer have contributed in the field of health communication. The accomplishments of coping strategies

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<sup>22</sup> Feedback and social control suggests social networks can enforce, reinforce, and/or alter (un)healthy behaviors and (un)healthy lifestyles.

<sup>23</sup> Health information and seeking care suggests support helps patients manage uncertainty by giving, and/or helping patients interpret, health information, which influence health outcomes.

<sup>24</sup> Assistance with health behaviors and healthcare suggest social networks function as physical resources, aiding patients in various ways, from financial support to homecare.

<sup>25</sup> Helping cope with stress suggests network members can assist patients coping with problem-focused and/or emotion-focused stressors.

situated in and among uncertainty, information, and support have exposed communicative dimensions of coping with stress through seeking, managing, and sharing information about cancer. These contributions have provided invaluable data. For example, Eheman et al. (2009) have investigated the cancer patients' needs for information resulting from uncertainties associated with cancer. Walsh et al. (2010) have examined how information and informational sources influence a patient's decision for treatment. Health communication research on coping through social support and social networks spotlight how sharing information can (re)inforce and/or alter (un)healthy behaviors and/or lifestyles influencing health outcomes (Albrecht, 2011). These social scientific approaches to coping with cancer are necessary and must continue; however, some qualitative researchers in health communication have turned to narratives and the relationship between illness and narratives. Illness narratives can expose a type of coping with uncertainty and uncontrollability through the act of storytelling.

### **Narrative Approaches and Health Communication**

Narrative theory rests in part in its focus on webs of interwoven social (and material) forces. No story is solely personal, organizational, or public; personal stories cannot escape the constraints of institutional interests, nor are they separate from cultural values, beliefs, and expectations. Meanwhile, institutional structures and scripts intertwine to form the social milieu in which performances unfold (Sharf, Harter, Yamasaki, & Haidet, 2011, p. 8).

Stories are a pervasive, even foundational, form of human communication. Human beings are storytellers and story listeners. Storytelling brings people together, making it a shared communicative act, one that is transactional, co-constructed, and constitutive. In the communicative transaction between a storyteller and a story listener, the teller has intent for telling a story, and the listener interprets meanings in, receives effects from, and gives feedback when, hearing a story. However, stories are not merely transactions between sender and receiver, but a shared act in which both teller and listener co-create. The shared telling and listening

produces and reproduces sociocultural meanings embedded in the story's use of language and narrative elements: narration, plot, role, metaphor, action, symbolism and more. A framework that accounts for narrative elements of coping with cancer can reveal how stories help patients cope with uncertainty and uncontrollability. A personal cancer story reclaims the narrative wreckage caused by cancer's biographical disruption. In telling a cancer story, the storyteller arranges fragmented pieces of their cancer experiences, re-constituting how one sees oneself in one's own story, how one describes one's feelings of coming undone, and the value one develops from and through one's cancer experiences. Stories then account for an individual's dialectical movement through the cancer journey, uncovering a fluid and dynamic identity emerging from uncertainty and uncontrollability.

Narrative inquiry, especially through deep analysis of text, is not a new approach in the academy. Joseph Campbell's (1949) work in comparative mythology and narrative patterns had exposed the "monomyth" or the shared organizational framework underlying the epic journey of heroes in mythical stories. Campbell drew this framework from French anthropologist van Genep<sup>26</sup> (1909), who had indicated three stages for rites of passage: "separation, liminality, and incorporation." Campbell's (1949) monomyth similarly divided a hero's journey into three parts: separation (pre-liminal), initiation (liminal), and return (post-liminal). Pervasive narrative structures underlying shared stories reveal the influence stories have on sociocultural systems of meaning. Four to five decades ago, the Narrative Turn surfaced across many disciplines in the humanities and social sciences (Sharf, 2017), shifting research from deep analysis of narrative elements to include a narrative framework for human understanding and meaning making. "In

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<sup>26</sup> In the following chapters, I discuss van Genep's work on rites of passage in more detail and expand upon van Genep's concept of liminality through the anthropological work of Turner.

communication studies, it was asserted that to conceptualize and articulate experience in story form is an innate human capacity such that narrative constitutes a paradigm” (p. 32). Humans are storytelling beings. A narrative paradigm provides a perspective to view stories as building blocks constructing sociocultural systems of shared meanings, values, beliefs, and ideologies (Fisher, 1984; Bruner, 1991; Levi Strauss, 1966). In this framework, narratives greatly influence individual interpretations of human experience. People are born into a world of stories containing narrative elements through which people partly make sense of experiences, thoughts, emotions, feelings, and bodily actions. One such experience and its related elements is that of illness.

### **Illness Narratives**

Sociologist Arthur W. Frank (1995) offers three main types of illness narratives, often intersecting in a single illness story: the restitution narrative, the chaos narrative, and the quest narrative. These narrative types have provided and still provide a framework for some narrative researchers in health communication (Sharf, 2017; Babrow & Mattson, 2011; Harter, Japp, & Beck, 2005; Harter, Kirby, Edwards, & McClanahan, 2005; Beck, Harter, & Japp, 2005). Frank notes the restitution narrative as the most common and preferred narrative, which is especially true for patients recently diagnosed (Frank, 1995, p. 77). I extend on Frank’s types by adding a cancer narrative through what other researchers have said about cancer stories. These various narrative types show how uncontrollability/controllability is often central to one’s illness story.

#### The restitution narrative

The restitution narrative chronologically organizes a story; storytellers begin this type of illness story when they are healthy, then they move to unhealthy and medical treatment, and end when treatment restores health or looks forward to treatment restoring health. Thus, there is an underlying healthy/unhealthy dialectic in the restitution narrative. Like van Gennep (1909) and

Campbell (1949), three similar stages underlie a patient's journey in the restitution narrative: pre-liminal,<sup>27</sup> liminal,<sup>28</sup> and post-liminal.<sup>29</sup> The restitution narrative, which is the dominant biomedical narrative, has a "telos of cure" (Frank, 1995, p. 83) for its post-liminal stage. Biomedicine predicates itself upon an ideal that normal bodies are healthy bodies: free of illness. To be ill is to be abnormal. In this frame, medicine intends to treat the body, returning the body back to health. From pharmaceutical advertisements to conversations in medical organizations, the circulation of the restitution narrative is pervasive in personal, public, and institutional discourses on health; it functions as the "model of how illness is to be told" (p. 78). Through individual internalization of the restitution narrative, being healthy becomes a sociocultural norm. Physicians and patients derive an ethic, or set of expected actions, from this narrative. If the telos is survival, or cure, then a physician plays the role of active hero and a patient has a passive role (p. 93).

The restitution narrative is about controllability over illness through medical treatment and cure; however, this makes diagnosis of disease an uncontrollable matter for a patient. By authorizing physicians, nurses, and medical staff the authority to seek control over a patient's illness, this narrative type leaves patients impotent, unable to control the health outcome. The restitution narrative affords a patient little, if no, agency to restore control over disease or illness in one's body (Frank, 1995). A patient's actions then are passive in this narrative journey, a patient should follow medical orders, and allow medical authorities to treat their bodies. In fact, a patient's body becomes an object of medicine, objectified by the medical gaze and its authority to treat and to commodify the unhealthy body as a site for medical intervention. Whether patients

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<sup>27</sup> The pre-liminal stage occurs just before, and/or when, noticing symptoms (Frank, 1995).

<sup>28</sup> The liminal stage occurs at, and after, diagnosis (e.g. treatment) (Frank, 1995).

<sup>29</sup> The post-liminal stage occurs when completing, and after, treatment (Frank, 1995).

follow medical orders, patients experience uncontrollability associated with disease and/or illness partly because the restitution narrative, often known as the biomedical narrative, does not allow patients to have control over the outcome of the story. A patient's appraisal of the situation as uncontrollable directly relates to transactional coping (Lazarus 1967; Lazarus & Folkman 1984). "On the control dimension, the teller of the restitution story wants the body's former *predictability* back again" (Frank, 1995, p. 85). In the telling, patients reconstitute its narrative structure (pre-liminal, liminal, and post-liminal) along with a physician's active role and a patient's passive role.

#### The chaos narrative

The chaos narrative is without structure and based on the fragmented experiences in which patients do not expect to survive. The lack of order in the chaos narrative makes it more of an "anti-narrative" (Frank, 1995, p. 98): non-chronological, non-structured, non-normal, and non-pleasant. Most people do not want to hear or even to tell the chaos narrative. For Frank, "true chaos stories cannot be told" (p. 105) because chaos has no purpose, there is no aim and/or goal of restitution driving the storyteller's actions in the story. However, patients can weave the chaos narrative in and out of their illness stories, but rarely is an illness story fully chaotic. In addition, the chaos narrative has no temporality in its sequence, and patients may even use the present tense when talking about past, present, or future experiences. The chaos narrative articulates lived fears and frightful experiences associated with disease, suffering, and death. Chaos stories resist the restitution narrative for the belief that medicine controls a health outcome, as well for its lack of compassion for suffering. Thus, chaos is about the disordering of order, the unraveling of the biographical self—a collision between one's personal narrative and

the anti-narrative—leaving the patient in a liminal stage, situated between two worlds, wherein uncontrollability and uncertainty is a matter of identity.

The chaos narrative is about uncontrollability from illness. Like the restitution narrative, the chaos narrative places a patient in a passive role, vulnerable to external forces. In this narrative type, “no one is in control” (Frank, 1995, p. 100) of the patient’s health outcome. “On the control dimension, the body telling chaos stories defines itself as being swept along, without control” (p. 102). Despair can become an inescapable “feedback loop” (p. 102) rendering patients as inconsolable. The chaos story is a disruption to one’s biographical self. The patient unmakes his or her world through negative contingent statements such as “and then this happened, and then that happened, and then this happened,” and so on and so forth. The chaos narrative describes victimization to disease or illness, as the patient is passive to external forces doing consistent harm to his or her body. When hearing a chaos story, the impulse might be to remove the patient from the chaotic narrative; however, being in the chaotic narrative allows the patient to experience the “narrative wreckage” (Frank, 1995, 110). Later, turning back on this wreckage can allow for transformation. Physicians and other medical staff might interpret patients who tell the chaos narrative, as depressed, placing them back into the biomedical narrative of treatment (e.g. pills for depression).

#### The quest narrative

The quest narrative is closest aligned with Campbell’s (1949) monomyth, or the hero’s narrative journey of separation, initiation, and return. Like the monomyth and the restitution narrative, the quest narrative uses a pre-liminal, liminal, and post-liminal structure, though not necessarily chronological. In fact, “both restitution and chaos remain background voices when the quest is foreground” (Frank, 1995, p. 115). In the monomyth, the hero’s quest starts with a



call to duty, a responsibility that *separates* the hero from ordinary life. For Frank, separation in illness stories begins with bodily symptoms, calling the person into the journey of illness, wherein diagnosis is the threshold into liminality. The newly diagnosed patient embarks on a trying journey, as the medical protocol sets the course for ritual actions that *initiate* the patient into the world of illness. A patient's reflexivity of this initiation is distinct to the patient's transformation from the illness journey. "Only at the end of initiation does the teller conceptualize what has been going on as an initiation, thus organizing the experience as coherent and meaningful" (p. 118). In the final stage, the transformed patient "*returns* as one who is no longer ill but remains marked by illness" (p. 118). Through turning back on the agonistic experiences between being healthy and being unhealthy, the patient's testimonial tells a story of bearing witness to the struggle of being and becoming in a new world.

Three types of quest narratives can intersect in the telling of an illness story: *memoir*, *manifesto*, and *automythology*. Quest *memoirs* "are not told chronologically" (p. 120). They are often an autobiographical story interrupted by fragments of an illness narrative. People who have public status typically author memoirs, and the author's concern for the public's interpretation of the story inflects the telling. "The memoir is the gentlest style of a quest story" (p. 120). Tellers contain the chaos experienced in the illness through both delivery and content of the story.

If memoirs are the gentlest, then manifestos are the roughest. *Manifestos* involve the lived suffering and chaos experienced from illness. Patient suffering becomes the truth about the illness experience. Because biomedical models hide this truth, patient actions seek to expose suffering and enact change. A return to health (or normal) is neither the goal nor the journey in the manifesto quest narrative; however, patients become heroes through actively seeking to increase rights and/or even enact social transformation. Frank offers a disability story as an

example of the manifesto. In the story, the patient talks about not wearing a prosthesis after a mastectomy and the public treatment—if not punishment—she received for doing so. The patient’s doctors told her that by not wearing her prosthesis, she was making others uncomfortable. Her resistance to wear the prosthesis exposes the social conflation of a healthy body as a normal body. The impact of social expectations (e.g. women have breasts) placed upon her body reveals a post-liminal stage that can return a patient to good health, rather than return a patient to a normal body.

The *automythology* is a story of rebirth and new identity, the narrative wreckage from an illness experience catalyzes a transformation of self (Frank, 1995, p. 123). Unlike the socio-political action sought in the manifesto, the action in automythology reshapes individual identity. In this type of quest narrative, there is still a modernist ideal and telos of normal underlying the narrative structure. Patients become heroes in their own stories as they actively seek to control the uncontrollability of illness. In this type of quest narrative, patients seek and use alternative resources (outside of medical treatment) to restore the body’s health.

The quest narrative is about (un)controllability wherein a patient is the active agent, or hero, in the illness story. The patient has agency and, thus, a sense of control over the uncontrollability associated with illness. “Quest storytellers write of their own bodies, including pains and disfigurements, in sensuous detail” (Frank, 1995, p. 127). In a patient’s journey through the chaotic contingencies experienced in illness, the patient learns chaos and its uncertainty of contingency is the only certainty. This is especially true in an automythology quest narrative, wherein a patient’s actions seek and/or use alternative resources to manage the uncontrollability of illness. As an example of automythology, Frank cites Cousins, (1981) *Anatomy of an Illness as Perceived by the Patient*. Russian physicians had diagnosed Cousins

with an acute inflammatory disease, which had a debilitating and incurable prognosis. Cousins used a mixture of approaches including a regimen of humor, believing laughter was important to recovery. Cousins' friend, and physician, had said, "his biggest job was to encourage to the fullest the patient's will to live and to mobilize all the natural resources of the body and the mind to combat disease" (p. 44; Frank, 1995, pp. 124-125). The quest narrative makes the survivor of cancer a hero of their own story.

### Cancer narratives

The available structures themselves for storying illness can make and keep us ignorant about cancer. I want to add that the conventional features of the personal narrative are so well established that even those authors who try to write against the standard story often, in the end, just wind up writing it again (Segal, 2007, p. 14).

Cancer narratives may include any combination of the restitution, the chaos, or the quest narrative, wherein language adds a new element to illness. Sontag (1978) described the use of metaphoric language in cancer stories as "the language of warfare: every physician and every attentive patient is familiar with, if perhaps inured to, this military terminology" (p. 64). Military language and themes of bravery and heroism serve the restitution narrative and the quest narrative, wherein heroes struggle with the chaos associated with cancer. In the restitution narrative, military language gives agency to biomedicine's role in treating or curing the cancer patient: "cancer cells colonize," "invade," "[or] are invasive" "[and] treatment aims to 'kill' [or destroy] cancer cells" "[and] patients are 'bombarded' with toxic rays. And chemotherapy is chemical warfare" (pp. 64-65). Physicians are the heroes of restitution stories, using medicine and medical procedures to battle cancer and save patient lives. In the quest narrative, military language gives agency to the patient's role in surviving cancer. Patients see themselves as actively fighting or battling cancer, and they are the brave heroes of their own stories. In both

restitution and quest cancer narratives, patients are victims to the chaos of cancer and the uncontrollable and uncertain effects from diagnosis.

The goal in these two narratives is patient survival, restoring health through treatment or cure; however, there is often a conflation of cure as the restoration of health. After cancer, a person's bodily health does not necessarily return to its "previous physical condition" (Frank, 1991, p. 19). In many ways, the experience of cancer can leave the patient permanently marked. The restitution and quest narratives present a dialectical structure, wherein order controls the disordering of the body and the chaos associated with the liminality of cancer. Cancer stories detail a patient's "struggle against adversity" (Stacey, 1997, p. 1). The intention behind curing a patient is to restore health and, as such, to return the body back to the social order as normal. Cancer narratives then "provide a means for conveying the biographical disruption caused by illness . . . Rather than stories about illness, such accounts are better characterized as being about a life disrupted by illness" (Mattingly & Garro, 2000, p. 27). Disrupting life is a theme in cancer narratives and can act as the catalyst for patient transitions and/or transformations—the patient has "faced death and . . . recognized the inevitability of human mortality" (Stacey, 1997, p. 1). When a patient moves from victim to victor, from unhealthy to healthy, from disorder to order, the patient's movement is a dialectical journey through liminality.

Cancer disrupts one's biographical life, threatening a patient's stable identity (O'Hair, Scannell, & Thompson, 2005; Hunt, 2000). In the act of telling a personal cancer story, the storyteller arranges the narrative wreckage experienced from cancer, reclaiming the body to reconstruct a disrupted identity. These reconstructed narratives can articulate transformation of the patient, during which a cancer story negotiates and reconstitutes identity (Frank, 1995; O'Hair, Scannell, & Thompson, 2005). Through telling strategic cancer narratives, "patients

provide a revised notion of order that restructures their disrupted identities in ways that transcends victimhood” (Hunt, 2000, p. 100). Because individuals control the telling of their own story, “[cancer] narratives can function as indicators of how individuals define their illness and their identity” (O’Hair, Scannell, & Thompson, 2005, p. 219). When cancer patients tell restitution and quest narratives, patients must move from victim to victor over cancer, becoming a survivor of the disease. For Frank (1995), survivor stories are testimonials. To be a survivor of disease is to be a witness of a fragmented truth of illness, one rooted in personal experiences of seeing suffering and being a sufferer (Frank, 1995). In the being and becoming, the survivor’s body is then its own testimony of illness, the body is complicit in cancer, and in the telling of a cancer story. “The performative nature of narrative is especially compelling when considered in terms of the permanent disruptions to identity” (Hunt, 2000, p. 89). A focus on disruption of order and the chaos involved in liminality is perhaps more important than Frank (1995) notes. Liminality is not merely a stage of illness in which one’s story must move through to achieve restitution or quest; liminality is the space of anti-structure—or the anti-narrative—it is the space of possibilities and change; it is the space of a liminal identity. Performance theories can contribute much to the concept of liminality and identity.

Despite medicine’s movement towards a biopsychosocial subject that recognizes “the interplay between the body and communication” (Babrow & Mattson, 2011, p. 21), health communication research has placed little attention on the performing body and its relationship to an uncertain and uncontrollable cancer identity. Health communication’s substantial research on coping with cancer’s uncertainty, has also paid less attention to the uncontrollability of cancer and nearly no attention to adolescent cancer patients. This dissertation calls scholars in narrative studies and performance studies to see the field of health communication as wanting of

humanistic research that critically examines the reflexive interplay between bodily performances and narratives. The performing body's relationship to identity, discourse, narrative, others, culture, and society makes an adolescent's embodied telling of a cancer story an important performance for analysis.

### **CHAPTER 3 CRITICAL, SELF-REFLEXIVE, AND PERFORMATIVE (AUTO)ETHNOGRAPHY**

Ethnographers occupy a literary borderland somewhere between writers who reach for very general audiences and those who reach for a specialized few. To the generalists, ethnography always seems pinched and inelegant, its standards stiff and restrictive. To the specialists, the same writing may seem imprecise and unfocused, its standards loose and unfathomable (van Maanen, 1988, p. ix).

Throughout chapters four and five, as a methodological approach, I use a critical and a self-reflexive performative writing (Spry, 2001). In Chapter 4, I poetically texture my present coping experiences with the prose of my cancer story and various academic theories. In Chapter 5, I use this approach to engage four videos of teenagers telling a “My Cancer Story” online and for public audiences. In this chapter, I situate performative writing in ethnographic scholarship, by first defining what ethnography is. Next, I give a brief history of ethnography. Then, I situate performative writing as a critical and self-reflexive (auto) ethnographic approach. Finally, I discuss why I use this method, ending with a brief outline of how I use this approach in the next two chapters.

#### **What is Ethnography?**

The study of ethnography roots in the discipline of anthropology, but has branched into several academic disciplines, sub disciplines, and fields as an approach to study a group of people, a culture, or a society (van Maanen, 1988, Lindloff & Taylor, 2011; Madison, 2012). The word ethnography derives from the Greek words: “ethnos” and “graphos.” Ethnos means a nation, a culture, or a society. Graphos means to record, a recorder, or something recorded. Thus, ethnography is both a process and a product. As a process, ethnography is a method of various research activities ethnographers use to explore and to record a group of people. As a product, an ethnography is a record of a group of people, recorded by an ethnographer.

The ethnographer acts as a subjective researcher and as a storyteller. As a researcher, the ethnographer's body and his or her senses function as the primary tool for ethnographic research, along with his or her knowledge of theories and methods. van Maanen (1988), an anthropologist, indicated ethnographers use a combination of field notes, participant-observation, and interviews to collect data on other groups of people, cultures, or societies. In contemporary ethnography, these research activities evolved to include conversation analysis, documentation analysis, self-analysis, oral histories, mapping, and more (Madison, 2012, Lindloff & Taylor, 2011; Fetterman, 2010). Field notes offer thick descriptions of the cultural contexts an ethnographer encounters and the experiences he or she has through deep involvement in daily practices, rituals, customs, and traditions with group members. These detailed accounts create an academic body of knowledge furthering the practice of ethnography. As a story teller, an ethnographer constructs records of his or her experiences into rich detailed narratives for audiences, who are often academic, but also can be public. These ethnographic stories give voice to the experiences of underrepresented or marginalized groups of people. This type of interpretive work records the rich complex relationships involved in a group of people along with the culturally symbolic systems of shared meanings people produce and reproduce through language and action.

Ethnography often falls under an interpretivist or critical interpretivist paradigm. Interpretivism takes a constructivist approach, focusing on human experience and world-making rather than truth-seeking and world-naming (Lindloff & Taylor, 2011). Ethnographers interpret groups, societies, or cultures through their sensory experiences, wherein they cognitively negotiate what they see, hear, smell, taste, and touch. Critical ethnographies apply critical theories to explore sociocultural actions, while seeking social justice through the emancipation of oppressed people, and a telos of sociocultural transformation. Critical theories then question truth



and how truth operates as a hegemonic force in and through sociocultural systems, delimiting subjectivity, and subject agency. For critical ethnographers, the way things are should/could be different. A brief history of ethnography can expose problems in the field's early paradigmatic assumptions and approaches to research, which a critical and/or reflexive ethnography sought/seeks to improve.

### **Brief History of Ethnography**

Logical positivism, colonialism, and imperialism influenced early ethnographic research (van Maanen, 1988). Logical positivism derives from positivism, which is an epistemological paradigm that suggests, in a Cartesian way, that truth is out there and discoverable through observational and measurable enquiry (Denzin, 2001). Logical positivism applies a systematic reduction to positivism, suggesting knowledge must be observable and verifiable to have useful meaning. These isms led to an etic approach in doing early ethnography, wherein ethnographers distanced themselves from the cultures they observed and recorded (van Maanen, 1988). The ideals underlying much of the work by early ethnographers led to an observational and objective approach to studying others. These researchers rarely participated in cultural practices, rituals, ceremonies, or activities with members of the groups, societies, and cultures they studied.

At the turn of the twentieth century, the process of ethnography moved away from its distanced observational approach and toward participant-observation as a principle when studying culture (Mead, 1928; Malinowski, 1929). However, positivism and its distanced approach inflected an early belief behind participant-observation: ethnography shared rich, concrete, complex, and unbiased accounts of others. In addition, many ethnographers using a distanced approach wrote their ethnographies in the present tense (Madison, 2012; van Maanen, 1998) and ethnographic representations of others became fixed in a timeless present. An

ethnographic present is a “literary illusion suggest[ing] that cultures stand still through time” (Fetterman, 2010, p. 127). Geertz (1968) questioned a social scientific research ethic and its underlying distanced approach, uncovering a moral dimension in ideals guiding ethnography. Many early ethnographies commodified the cultural other, for example the term “exotic mongering” (van Maanen, 1988, p. 39) references how researchers exoticized cultural artifacts and cultural others, objectifying and dehumanizing the people whom they studied. Later ethnographers situated their research against early ethnography, recognizing the consequences of ethnographic representations, like exotic mongering (Marcus & Fisher, 1983).

As ethnography grew further away from its positivistic roots, and into interpretivism, participant-observation evolved to a “Deep Hanging Out” (Geertz, 1998), wherein ethnographers immersed themselves within a group, a society, or a culture. This approach may earn an ethnographer trust among others, affording the ethnographer access to informants who authorize more authentic group, social, or cultural experiences. However, for Madison (2012), “meanings can never be fully present, apparent, or authentic in human consciousness—true meaning is always colored and filtered through . . . consciousness” (p. 70). Like exoticizing, when ethnographers seek authenticity, they seek an authentic aesthetic, one that delimits other possibilities of experiencing a group, a society, and/or a culture. Madison (2012) also suggests participation should be more than an ethnographer’s immersive experiences within a group of people. Ethnographies should account for how ethnographers co-construct shared experiences with the members they study through dialogic writing practices.

### **Critical and Self-Reflexive (Auto) Ethnography: A Performative Writing**

Critical ethnography maintains a degree of social action and/or advocating for issues of social justice (Madison, 2012). These ethnographies ground themselves in critical theories, and

typically seek a transformation of the ethnographer and/or his or her audience. Critical ethnographies critique to expose how dominant ways of being in a group, society, or culture marginalize and suppress other members or ways of being in the world. The critical ethnographer explores the underlying sociocultural structures that produce and reproduce daily practices, customs, and rituals in a group, society, or culture along with their shared symbolic system of meanings. Critical ethnographies speculate how sociocultural forces inadvertently mask, if not intentionally conceal, the marginalization those structures create.

Goodall (2000) proposed a new ethnography, one that is critical and reflexive. A reflexive approach endorses a turning back on the subjective position of the researcher. Ethnographers become accountable for the power and/or the authority imbued upon them through their research paradigms and individual positionalities. Goodall's self-reflexive process claims writing as a method of inquiry, one that is "dialogic" (p. 41), and accounts for the researcher as a "self-examining narrator" (p. 23). In a dialogical approach, a researcher foregrounds his or her presence as a subjective self and the self's understanding of others. A dialogical approach in ethnography can capture the co-creation of meaning by blending two or more voices together. Self-reflexivity then considers the researcher's subject position in relation to other subject positions, highlighting detailed accounts of how the researcher experiences a group, a society, or a culture (Spry, 2006). Madison (2012), outlines three ethical responsibilities for ethnographers conducting critical reflexive research: (1) to foreground the power in the ethnographer's positionality; (2) to seek a dialogical representation of others; and, (3) to unmask how sociocultural power operates to marginalize the experience of others.

Some academics consider a critical reflexive ethnography "as autobiographies or autoethnographies" (Goodall, 2000, p. 9). Though there are similarities among these, a critical

and reflexive ethnography “is not limited to these two genres.” In fact, autobiographies, and what van Maanen (1988) calls confessional ethnographies, focus on the ethnographer’s story rather than members of the group, society, or culture they study. Although a confessional ethnography can illuminate cultural context (Madison, 2012, p. 198), Terry (2006) argues confessional ethnographies are individualistic and serve a cathartic purpose for the storyteller, hindering dialogism. Autoethnographers use self-reflection and/or detail the presence of the autoethnographer in culturally symbolic realms, describing personal accounts of their membership in a group, a society, or a culture. These stories often reveal subjugated knowledge, wherein the researcher offers his or her subjective experiences being within a marginalized group (Madison, 2012; Ellis, Adams, & Bochner, 2011). From autobiography, confessional ethnography, and autoethnography:

We learn a great deal about the personal reconstructed and autobiographical history of the author, but very little about how that history connects to the lives and accounts of cultural others. The result can be an overly self-ish text that may have great personal value for the writer (and this should *never* be discounted) and perhaps even some provocative value in generating dialogue, but that doesn’t achieve the goal of *balancing* the inward and outward representations. (Goodall, 2000, p. 91).

For Goodall (2000), autoethnographers may neglect the relationship of the self to others. However, critical reflexive autoethnographies can record personal experiences to illuminate the social constitution of the self, and an identity shaped and reshaped through others who produce and reproduce sociocultural systems of power (Madison, 2012). Critical reflexive autoethnographies then orient readers toward the reflexivity between the author’s self, contextualized within culture, and in relation to others. “Giving an account of oneself always and already involves an account of who we are with others” (Spry, 2016, p. 39). Critical reflexive autoethnographies can highlight an author’s experience to expose forces shaping the self and others such as language, context, narratives, and performatives.

In the remaining chapters of this dissertation, I draw from the works of Goodall (2000), Pollock (1998), Madison (2012), and Spry (2006; 2016) to use a critical and reflexive (auto) ethnographic approach through performative writing. I ground my method in Goodall's (2000) new ethnography: asserting writing as a reflexive method of inquiry through "personally and academically reflecting on lived experiences in ways that reveal the deep connections between the writer and his or her subject" (p. 137).

From Pollock (1998) and Madison (2012), I recognize the ethical concerns with performative writing as a method of inquiry. Not only does performative writing have a stylization entrenched in its own historical and aesthetic conventions, but also it is fraught with the perlocutionary danger of what words can do, even having the potential to "unhinge or override its [own] claims" (p. 80). Moreover, I write within and around Pollock's suggested six-part framework for performative writing as: evocative,<sup>30</sup> metonymic,<sup>31</sup> subjective,<sup>32</sup> nervous,<sup>33</sup>

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<sup>30</sup> "Performative writing "evokes worlds that are other-wise intangible, unlocatable: worlds of memory, pleasure, sensation, imagination, affect, and in-sight" (Pollock, 1998, p. 80).

<sup>31</sup> Performative writing can recognize "the extent to which writing displaces, even effaces 'others' and 'other worlds' with its partial, opaque representations . . . often obscuring them in the very act of writing, securing their absence with the substitutional presence of words" (Pollock, 1998 p. 83).

<sup>32</sup> Performative writing has "two preliminary moves: first, shifting from *positioning* the self . . . to articulating the motive, shaping relations among selves in an ongoing process of (self-) production; and second, shifting from documenting 'me' to reconstituting an operative 'we'" (Pollock, 1998, p. 87).

<sup>33</sup> Performative writing "crosses various stories, theories, texts, intertexts, and spheres of practice, unable to settle into a clear, linear course, neither willing nor able to stop moving, restless, transient and transitive" (Pollock, 1998, pp. 90-91).

citational,<sup>34</sup> and consequential<sup>35</sup> (pp. 80-96). For Pollock, performative writing uses evocative language to entice the reader to enter a new imaginative world created through stringing together words that stand in for what is absent. However, the referential meaning of a word is at best obscure, troubling the process of my subjective interpretation, blurring my meaning and the possibility of discovering truth. For Pollock, truth is not the telos of performative writing. Performative writers intend to expose social consequence through a program that weaves together various texts stories, poetry, theories, academic prose, along with quotations by academics, the author, and others. Like Pollock, Madison (2012) purports a performative writing that is critical, reflexive, and dialogic. Drawing from Pollock's (1998) six-part framework, Madison (2012) offers performative writing as an alliteration: "to embrace;<sup>36</sup> to enact;<sup>37</sup> to embody;<sup>38</sup> to effect<sup>39</sup>" (p. 220). I extract from her alliteration<sup>39</sup> a performative writing that stitches

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<sup>34</sup> Performative writing "stages its own citationality, *re-sighting* citation, displaying it in an accumulation of quotations or self-quotation or quotation from beyond the borders of academic prose." (Madison, 2012, p. 94).

<sup>35</sup> Performative writing "appeals with the affective investment of one who has been there and will be there at the end, who has a stake in the outcome . . . [which breaks] the discursive limits of the emperor's stage and invigorating the dynamics of democratic contest in which the emperor and his new clothes (or lack thereof) are now continually refigured" (Madison, 2012, p. 96).

<sup>36</sup> Performative writing is "is welcoming and encompassing and aims to meet the reader with both affect and affection . . . you write to make a difference to them . . . [and] some kind of contribution" (Madison, 2012, p. 220).

<sup>37</sup> "Performative writing constitutes enactment because it is a braiding of poetry and reportage, imagination and actuality, critical analysis and literary pleasure . . . [it] renders 'absence presence'" (Madison, 2012, p. 223).

<sup>38</sup> "Performative writing as something embodied means . . . meanings and experiences in the field are filtered and colored through sensations of the body . . . and bod[ily] knowledge comprises impressions and interpretive meaning" (Madison, 2012, p. 227).

<sup>39</sup> "Performative writing is conducive to critical ethnography because it embraces political struggle and is not ashamed of its politics and advocacy" (Madison, 2012, p. 230).

together poetry and prose, fragments of stories and academic theories in ways that greatly consider my reader, as well as the effects my words have on others and in the world. I write to invite my reader into a world of teenage cancer stories mediated by my bodily senses and interpreted through my bodily sensations and from bodily knowledge. As Madison notes, I use my body to engage critically and reflexively cancer stories; I hope to unmask a world of teenage cancer for my reader, exposing an underlying agonism through which power subjugates one's narrative role and identity through the telling of becoming and being a teenage cancer patient.

A critical reflexive (auto) ethnographic approach is “foundational in a performative-I methodology” (Spry, 2016, p. 39; see also Spry, 2006) and can help to illuminate coping with a cancer identity. The Performative-I examines the subjective position of the researcher to challenge and to critique dominant and privileged cultural structures where performance and language produce and reproduce sociocultural power. Throughout the next two chapters, I seek most, if not all, of the following principles from Spry's (2016; 2006) performative-I: “(1) textual forms as effects of the fragments and wreckage of experience, (2) an empathetic epistemology of critical and copresent reflection . . . transforming systems of dominance” (Spry, 2006 p. 341), (3) illuminate my reflexivity to others by detailing “the effects of difference” (Spry, 2016, p. 41).

An ethical framework for critically and reflexively dialoguing personal narrative, auto-ethnographic, and autobiographical scholarship . . . to move beyond mere critical textualizing strategies of personal narrative to theorize the ethical dimensions of how we audience, engage, and respond to personal claims to experience (Goltz, 2011, p. 135)

I employ a critical and self-reflexive method of performative writing, grounded in the aims of the performative-I. I seek to expose narrative and performative systems of dominance subjugating teenage cancer patients telling cancer stories. I keep Goltz's (2011) concept of ‘critical frustration’ thus I do not critique through a lens of better or worse, but from one that intends to invite and “further generate alternative and resistant meanings” in my story and the

story of these adolescents. In the next two chapters, I hope to create a copresence between fragments of my cancer story along with others. I believe this can provide a dialogic way of understanding the act of coping, or an epistemology of patients coping with cancer's uncertainty and uncontrollability through which narratives and performatives of cancer can become criteria for analysis.

### **Why Critical, Self-Reflexive, Performative (Auto) Ethnography?**

What a patient says and does while telling a cancer story can expose complex cognitive and performative negotiations of coping with cancer's identity. In Chapter 4, my teenage cancer story explicates my narrative and performative negotiation of, and transformation to, a cancer patient. As mentioned in Chapter 2, Frank's (1995) illness narratives give insight to liminality as a perlocutionary effect from the speech act of a cancer diagnosis. My teenage cancer story can reveal my being 'betwixt and between' two narrative structures: my biographical narrative and my new role in a cancer patient narrative. I think the matter of coping with a cancer identity is especially true for many adolescent cancer patients. Adolescents often have a heightened awareness of their identities. The newly diagnosed teenage patient must incorporate cancer experiences into their body, where performances consciously and unconsciously negotiate the two narrative selves, or one's narrative identity. Narrative identity is the ongoing embodiment of one's narrative apperception.<sup>40</sup> Exposure and incorporation of illness narratives partly shape cancer patient identities, and in the telling of a personal cancer story, the storyteller articulates bodily experiences of coping with a new cancer identity. Engaging and analyzing stories for

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<sup>40</sup> For Ricoeur (1985), narrative apperception suggests, a person's exposure to narratives integrate into one's being and one's conscious through the performance of narrative roles in a narratively constructed reality (Ricoeur, 1985).



underlying narrative and performative elements embedded in the performance of telling one's cancer story facilitates insight to coping with a cancer identity.

Throughout the next two chapters, my experiences as an adolescent cancer patient inform my methodological approaches. Interviewing adolescents recently diagnosed with cancer is important but also intrusive during such a sensitive time. Adolescents are already a protected population from research and a cancer diagnosis is a particularly traumatic experience rendering them more vulnerable. I have a sensitivity for the adolescent cancer patient and especially so within hospital and clinic spaces, wherein my method intends to respect the experiences of patients and their families to allow them to cope. I remember how frustrated I felt when so many different people would come in and out of my hospital room, asking me questions, poking and prodding at my body. Having cancer is traumatic, and, at this stage of my research, I prefer to err on the side of giving adolescent patients and their families privacy. This is a personal ethical choice that can hinder lived experience and the presence of each storyteller; however, I do my best to engage a presence<sup>41</sup> through the interplay between trace<sup>42</sup> and aura<sup>43</sup> I experience when viewing each performed cancer story. Thus, I avoid face-to-face contact with adolescent cancer patients by utilizing critical, self-reflexive, performative (auto)ethnography.

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<sup>41</sup> Through a deep reading of Walter Benjamin's presence and aura, as well as Wallace Bacon's presence, Coonfield and Rose (2012) suggest digital media contests Peggy Phelan's requisite of the live body for the effect of presence in a performance. Presence surfaces through the experience of the object's aura and the trace effects of the performer evident through a performer's digital presence, yet live absence.

<sup>42</sup> For Benjamin (1999), "trace is the appearance of proximity, however distant what it left behind may be," the performer becomes present for an audience despite her or his live absence in reality.

<sup>43</sup> For Benjamin (1999), aura conceals the appearance of presence regardless how close the presence might be through trace. In addition, Coonfield and Rose (2012) suggest that aura is also a relationship developed with the person, the performer, the text, and the object producing the performance.

In Chapter 4, I employ a critical, self-reflexive, and performative autoethnographic method of My Cancer Story. This approach centers on the researcher's personal story situated in or against a social group's shared system of stories and actions, which can critically expose the relationship between and among discourse, action, and identity along with how discourse and action operate to maintain and/or resist groups norms and identities. I use my present experiences as a survivor of teenage cancer along with fragments of my cancer story to engage research on how adolescents cope with cancer. In so doing, I open critical narrative and performative theoretical dimensions to coping with cancer's identity.

In Chapter 5, I employ a critical, self-reflexive, and performative ethnographic method in viewing teenagers telling a "My Cancer Story," posted online and for public audiences. This approach centers on the ethnographer as an interpretive tool who listens to, makes record of, and sense of shared stories in a sociocultural group, which can also critically expose the relationship between and among discourse, action, and identity along with how discourse and action operate to maintain and/or resist groups norms and identities in the group. "Computer technology provides those living with illness a space to communicate their stories" (Mahato, 2011, p.212), and to share their cancer experiences with public audiences. I critically and reflexively engage four online videos of adolescents telling personal cancer stories. In my engagement, I continue to add fragments of my cancer story textured with a poetic writing of my present coping experiences when viewing the videos. I also offer academic prose in the application of the narrative and performative model from Chapter 4 as well as literature on coping from Chapter 2. This model creates a lens to analyze a teenager's embodied telling of a "My Cancer Story."

"Performative autoethnography is a critically reflexive narrative representing the researcher's personal and political intersections/engagements/negotiations with others in

culture/history/society” (Spry, 2011, p. 53). As mentioned previously in this chapter, (auto)ethnography is an exploratory method of enquiry through which a sociocultural group’s stories and performances are constitutive of sociocultural identities and the self. By contextualizing the sociocultural position of the researcher, critical self-reflexive (auto)ethnographies illuminate researcher subjectivities and cultural context through personal experience(s) (Madison, 2012). Critically reflexive autoethnographic work, however, does more than focus on the researcher, it places attention on sociocultural effects constituting othered bodies (Spry, 2016). In my approach, I apply a critically self-reflexive orientation (Alexander, 2006) toward adolescent cancer patients. I focus on cancer’s sociocultural effects narratively entrenched in adolescent cancer stories and a patient’s presentation of self through the physical embodiment of telling one’s personal cancer story. In doing so, I hope to expose how narratives and performatives constitute a cancer identity and the role narratives and performatives play in patients coping with a cancer identity. In addition, from a critical perspective, the performance of telling a cancer story situates within, or against, pervasive discourse on health and illness.

**CHAPTER 4**  
**“MY CANCER STORY:”**  
**FOR A NARRATIVE AND PERFORMATIVE MODEL OF COPING**

I tilt my head down and to the right,  
Bringing a cigarette to my lips.  
I raise the lighter to reach the cigarette’s tip,  
Rolling my thumb to spark its flint.  
Deep inhale.  
Slow exhale.  
Repeat.

My senior year of high school I had been a cancer patient for nearly a year when my oncologist found black specks under my tongue. He asked me if I was smoking cigarettes. I said, no. I lied. I tried smoking in middle school because I was curious, but I did not like it and it bothered my asthma. I started again when I had cancer. Maybe cancer is why I started? When it comes to cancer, the “why” is tricky. My oncologist told me it is not uncommon for teenage cancer patients to smoke. Then he lectured me. I mean, we all know smoking causes cancer, but who knew cancer causes smoking? They should include that warning with your diagnosis.

In this chapter, I articulate a narrative and performative model for adolescent patients coping with cancer based on the “fragments and wreckage” of my own lived experience of being a cancer patient (Spry 341). Coping with cancer was and is an ongoing matter of performing narrative identity. The narrative and performative turns exposed how narratives and performatives shape human subjects as meaning makers and identity makers. The narrative turn resurfaced an interest in a hermeneutic and metonymic logic, where subjective interpretations are understood through narrative discourses. Moreover, the mimetic reproduction of particular

narratives is (re)made through associations of language used in storying. From this perspective, subjects are understood as born into a narratively constructed reality, wherein individual identities come into being through performing narrative roles, constituting identity. A narrative subject reframes cancer's uncertainty to be a narrative matter, a subject's narrative identity must incorporate a new cancer patient identity. The performative turn adds to a narrative perspective by foregrounding the contingency and embodiment of identity: how bodily acts produce and reproduce subjective identities, where performed actions (re)materialize sociocultural meanings. From this perspective, uncertainty is a matter of the performative, through which patient bodies incorporate uncertainties of a cancer identity through everyday performances inside and outside the hospital. For example, the first time I had a bone marrow aspirate, spinal tap, fMRI, EEG, or any new procedure, diagnostic, or reaction to treatment I felt a high degree of uncertainty. Through the repeated doing of those actions, I begin to form my cancer patient identity. I suggest coping with trauma and stress associated with cancer is an embodied narrative apperception: a series of acts by a narrative and performative subject.

I draw on Fisher's (1984) "narrative paradigm" (p. 2), Ricoeur's (1985) "narrative identity" (p. 244) and Butler's (1988) "performativity" (p. 520), to offer a paradigm that shifts research from viewing patient coping as simply situated in an individual's cognitive/emotional appraisal or learned/dispositional responses, but also as an embodied narrative apperception. Embodied narrative apperception foregrounds the complexity of narrative identity and its negotiation of experiences associated with performing in the narrative role of cancer patient against one's pervasive identity and the various roles that make one's identity. The concept of embodied narrative apperception opens the door to various ways to explore a cancer identity and its narrative role. In this chapter, I propose a multi-theoretical argument: (1) a cancer diagnosis

and its narratives are language in action; (2) there is an uncertain and narrative liminality of all cancer patients, and of adolescent patients in particular; and, (3) that narratives and their discursive structures create performed actions, narratives, and narrative identities as much as they are created by performed actions, narratives, and narrative identities.

Coping is then a behaved reaction to a stressor and a performative act reflexively bound to narratives. In what follows I return to some of the scholarship on coping with cancer discussed in chapter two, unpacking the possibilities and limitations of this research in discussing my own lived experiences. Then, I turn to narrative paradigm, narrative identity, and performativity to situate my coping performances as performing negotiations of my narrative identity, demonstrating what these frameworks capture that the dominant approaches to coping with cancer often miss.

### **Coping with My Adolescent Cancer**

I started smoking with cancer.

Inhale.

I asked my doctors too many questions for my own good.

Exhale.

I worked out so often, I permanently damaged my right shoulder blade.

Inhale.

I stopped taking my medication.

Exhale.

I shaved my head to look more normal.

Inhale.

I did not speak to friends about my cancer.

Exhale.

I often think about cancer when I smoke.

Inhale. Exhale. Repeat.

Early scholars who researched coping with adolescent cancer have measured and categorized how patient behaviors sought to gain control and/or to reduce uncertainty associated with the disease and its treatment (Last & Grootenhuis, 2012). Results showed uncontrollability and/or uncertainty to be significant “sources of stress associated with increased emotional distress, including symptoms of anxiety and depression” (Compas et al., 2014, p. 2) in patients. As detailed in Chapter 2, the field of health communication has done extensive research in the area of uncertainty.

### **Coping with Managing Cancer’s Uncertainty**

Google did not exist, when oncologists diagnosed me. The internet consisted mostly of chatrooms, email, and limited search engines. Back then, I did not go to the internet for information, so I asked doctors and nurses a lot of questions. They would answer, and sometimes hand me a pamphlet or some other printed material on the subject. On the night of my diagnosis, the hospital gave me a four-inch three-ring binder, separated by fourteen dividers with all types of information on my cancer and its treatment. I felt overwhelmed. I still have the binder; it overflows with three years of cancer material. I have not read most of it.

Information and its uncertainty has had considerable attention from scholars in the field of health communication who study coping with cancer. In uncertainty management frameworks, coping develops because a patient experiences uncertainty associated with cancer. Scholars in health communication importantly examine how cancer patients cope with uncertainty through a patient’s complex management of information. Earlier health communication research on coping

with cancer's uncertainty measured patients active and passive information seeking behaviors. For these researchers, maladaptive coping surfaced when a patient intentionally avoided all information, an act known as "blunting" (Miller, 1995, p. 168) and/or when a patient excessively sought information, an act known as "monitoring" (p. 168). I was, and perhaps still am, a monitor. I asked my doctors too many questions for my own good. The night of my diagnosis, I badgered the attending<sup>44</sup> oncologist with questions. I wanted to know my odds of living. He hesitated, but I persisted until he responded: 'the blood in your bloodstream is 89.5% leukemic, patients with 90% and higher do not typically survive a week.' Then he left the room. I was not ready to hear that information. Later that night, the fellow<sup>45</sup> stayed in my room talking with me, I remember she tried to convince me that I was not a statistic, that I was not a number, that I was human being. She worried about how I was coping with cancer, so on the third or fourth day after my diagnosis, she invited another sixteen-year-old cancer patient to visit me in my room. I was angry she did this. I did not want to talk to him. I had nothing to say to him and I did not want to hear what he had to say. I just wanted him to leave. He invited me to a support group for teenagers with cancer, and he talked to me about a cancer camp for teenagers. I never went to either, but I still have the pamphlets inside the binder.

Researchers in health communication who investigated cancer's uncertainty also measured its nuances: addressing the sources patients sought to reduce uncertainty (Eheman et al., 2009); identifying patient demographics and information-seeking behaviors (Smith, Wolfe, & von Wagner, 2010); investigating the influences information and its sources had on treatment

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<sup>44</sup> An "attending" in hospital refers to the status of a physician, typically falling under chief and above a fellow.

<sup>45</sup> A "fellow" in a hospital refers to the status of a physician in a hospital, typically falling under attending and above resident.



decisions (Eheman et al., 2009; Walsh et al., 2010 ); examining how information-seeking impacted patient efficacy (Baurele et al., 2006; Kealey & Berkman, 2010; Niederdeppe, Frosch, & Hornik, 2008); and how information links to support by aiding patients interpretations of health information— influencing health outcomes (Goldman & Albrecht, 2011). However, my uncertainty was less about information and more about my life with cancer, less about what I did not know about my disease and more about how I was made unknown by it.

### **Coping with Adolescent Cancer Research**

The disruption of identity is an indispensable fact for adolescent patients diagnosed with cancer and is difficult with which to cope. The diagnosis of cancer causes a narrative wreckage for the patient, immediately impacting one's biographical story; this seems especially true for adolescent patients. Adolescence is a time of biological, social, and psychological development (Uba & Huang, 1999). Moreover, adolescence is a time of heightened ego, in which there is a heightened awareness of the body and its performances. Adolescent cancer patients not only cope with stressors related to cancer, they also cope with everyday life stressors associated with being an adolescent.

Five months into chemo, I remember my body had changed, I had a bloated belly from retaining water, a side effect from my meds. I went back to the gym, trying not to lose too much muscle, another side effect. After I had finally settled into a workout routine, the muscle around my shoulder blade stopped working. When I raised my right arm, my shoulder blade stuck out like a chicken wing. The neurologist said I had a damaged thoracic nerve, an injury typical of body builders, and not people of my small stature. For me, it resulted from a combination of a certain chemo— vincristine— along with the continued stress on the muscles and nerves from working out. The doctor told me to stop working out with weights while I took chemo, which I

did, but only for a couple of months. Today, when I try to work out with weights, in about a month my shoulder blade sticks out like a chicken wing. Treatment effects precipitated coping performances through which I attempted to preserve the visibility of my healthy body. My maladaptive and/or avoidant coping performance resisted my cancerous body. Inhale.

Psychological research on adolescents coping with cancer revealed some maladaptive and/or avoidant coping behaviors hindered patient livelihoods and patient futurities. For example, “some teenagers reassert their independence by skipping medications [which] . . . can lead to medical complications and an escalating cycle of avoidant coping” (Jones et al., 2013, p. 2148). During treatment, I stopped taking Septra for a few months. Septra is a sulfa based medication that my oncologists prescribed to me for the rest of my life and to prevent pneumocystis pneumonia. I guess some of the chemicals used in my chemotherapy made cancer patients, like me, more susceptible to that secondary illness, which has, or had, a high mortality rate for those infected. I am not sure why I stopped taking Septra. It was a daily horse pill; it was the only daily pill I took. When I started to take Septra, again, I broke out in rashes all over my body. My intermittent use caused a strange reaction to the drug. My oncologists told me never to take sulfa-based medications again. Five years later, this became a problem when I contracted a rare arthritis. It seems that sulfa-based medication is a primary drug for arthritis patients.

In addition to the disease and its treatment, a stigma surrounds the word cancer and the image of a cancerous body. Seen as diseased, sickly, and/or sometimes futureless, the newly diagnosed must negotiate negative perceptions of the disease. These perceptions are understood by a patient’s exposure and appropriation of public, personal, and medical narratives of cancer. Negative perceptions attributed to my cancerous body made my cancer diagnosis a greater hurdle to leap. The cancer body socially marks you. The loss of hair (from chemo and/or radiation

treatment), is a common signifier of a cancer patient, and was among the most traumatic experiences for me. I mean, your hair doesn't fall out right away. I had finally grown to like my hair, and I did not want to lose it. I asked one of my doctors when it would fall out, and she said it varies among patients. Over a month after my diagnosis, I decided to shave my head. I did not want to see it fall out. After the shave, my hair started to grow back, normally. I was hopeful I would be one of the lucky ones whose hair just thinned, which I had heard was a possibility. Incidentally, my hair never actually fell out, but two months later, I could pull it out. I was testing my hair daily and one morning it had died. I kept pulling my hair out, and out, and out—my head eventually had patches of hair. Later that day, my brother shaved my head, again.

Exhale.

One's appearance in social situations can affect adolescent patients more than others. The 'imaginary audience' (Elkind, 1967) posits a psychological theory of heightened ego during the psychosocial development of adolescents. Though scholars critiqued the concept for its egocentrism, researchers continue to use the concept to quantify degrees to which adolescents see themselves as social objects (Schwartz, Maynard, & Uzelac 2008). The theory addresses a person's, especially an adolescent's, unrealistic belief others are constantly watching and evaluating one's body and its social performances. Taking the theory into consideration, adolescents begin to comprehend a larger social world, including how they look and perform in the world. This reflects new cognitive capabilities, wherein adolescents use logic and reason to predict future possibilities (Ryan & Kuczkowski, 1994; Uba & Huang, 1999). Adolescents begin to form a social world with social consequences. Adolescents partially shape their identities through social performances, including new social (and narrative) roles: schools, jobs, friends, classmates, sports, clubs, and more (Uba & Huang, 1999). Peers and peer groups "gain

importance” (p. 351) during this stage of life, but social consequences, which result from peer interactions, heavily influence adolescent self-esteem and decision-making (Ryan & Kuczkowski, 1994). A year after my diagnosis, I went back to high school. It was my senior year. I had begun lighter chemo, and my hair had started to grow back. Though it was thin and scraggly, I was just happy to have hair, but once school started, I shaved it again. I mean, I knew that people knew I had cancer, but not everybody in school knew. Plus, my eyebrows were starting to grow, so I almost looked normal when I shaved my head.

Inhale.

Social roles, social performances, and their social consequences emerge during adolescence, constraining performance choices to conform to social conventions. Social roles and their dominant performances “represent a loss of autonomy” (Ryan & Kuczkowski, 1994, p. 222), delimiting agency. Social conventions can hinder adaptive coping by adolescent cancer patients. Social expectations of what I could and could not talk about with my friends prevented me from sharing my cancer experiences with them. After my diagnosis, a few of my friends visited me in the hospital. Unfortunately, my platelets were low, so my blood could not coagulate, and my nose bled like a leaky water faucet. My doctors pinched my nose closed, and then the blood drained down my throat. I could taste it. Soon after, I started vomiting blood. My oncologist sent me to the ENT, so they could cauterize my nasal passages. My friends were gone when I got back. They did not visit again. After that, I rarely spoke with my friends until I returned to school the next year. When I did, no one really said anything about my cancer, so neither did I. Research revealed adolescent patients “don’t want to talk about [their cancer]” (Van der Velden & Emam, 2013, p. 22) and/or perhaps do not know how to talk about cancer with friends. This lack of disclosure reduces social support, which, as mentioned in Chapter 2,

health communication has shown to be important for mitigating stress. Not disclosing cancer experiences to social networks can also reduce (dare I say, authentic) adolescent cancer narratives from circulating in public discourse. Reframing cancer patient coping as performing narrative identity in a narrative world offers new ways to view coping with cancer.

### **A Narrative and Performative Coping Subject**

Theoretical and methodological approaches that focus on the performing body as reflexively connected to narrative identity and narrative discourses add insight to questions of how patients cope with cancer experiences. Pace (2009) suggested narratives can explore questions of ontology as constituted by material bodies in discursive formations. Like Pace, I articulate a fluid (narrative) identity, contingent upon the performing body. I draw on a “hermeneutic phenomenology” (Ricoeur, 2007, p.38), “where phenomenology can be the presupposition of hermeneutics only insofar as phenomenology, in turn, incorporates a hermeneutical presupposition” (p. 43). The study of phenomena, or the relationship between an individual’s experience of objects and others along with the individual’s consciousness understanding of that experience rely on interpretation of text as much as the interpretation of text relies on previous experiences of phenomena. By placing a hermeneutic phenomenology within a “metonymic logic” (Worthen, 1995, p. 12), the performing body and its consciousness interpretation can become a “motile conflation of [textual] effects” (Spry, 2006, p.341). Through the interpretation of signs, the body and bodily actions can stand in for text as much as text can stand in for the body and bodily action. Using a multi-theoretical framework, I illuminate the circularity in how cancer narratives (re)shape and are (re)shaped by cancer patient performances, narrative identities, and cancer narratives.

“Narrative sense-making is not new in medical practice . . . [but] until recently, the explicit knowledge of narrative activity in clinical work was whispered on the fringes of mainstream medicine” (Sharf, Harter, & Haidet, 2011, p. 40). Narrative Medicine, a developing practice rooted in literary criticism, claims narratives inflect every part of medicine, where narrative medicine “forge[s] the intersubjective connection to sick people, and to fulfill the ethical duties incurred by hearing the stories of illness” (Charon, 2008, p. 25). Narrative Medicine champions physicians deeply listening to patients’ biographical stories, stories of illness, including stories from friends and family members. Listening to patient stories is imperative, and when patients’ personal narratives are set “against the backdrop of master narratives . . . personal narratives respond to the wreckage, the reclaiming, and the reflexivity [of the body] in postmodern times” (Langellier, 1999, p.126). Narrative Medicine is not absent of examining the body, the self, and narratives. Scholars of performance studies can further illuminate narrative medicine by adding the body’s contingency to identity through bodily acts, the body’s reflexive relationship to discourse, and how bodily acts produce and reproduce health cultures. However, health communication has yet to provide a narrative framework that investigates the performing cancerous body, and its relation to identities and to narratives.

### **Narrative Paradigm**

Several scholars have expressed paradigms based on narrative frameworks (e.g. Bruner, 1991; Fisher, 1984; Ricoeur, 1985). Narrative paradigm refers to narration as “a theory of symbolic actions—words and/or deeds—that have sequence and meaning for those who live, create, or interpret them” (Fisher, 1984, p. 2). Fisher does not restrict narration to the use of language, spoken or written, but also includes imagery and performed action. Narratives influence our sense making and meaning making processes by creating value to how a person

experiences the world. Narratives represent and organize experience. Narratives not only create public perceptions of how individuals should act and react in the world, but narratives offer possibilities of how to act and react in the world. Narrative paradigms use narratives to illustrate how human beings experience the world, make sense of the world, and make meaning in the world. Thus, the human subject is a narrative sense-maker, narrative meaning-maker, narrative world-maker, and narrative self-maker.

### **Narrative Identity**

Narrative identity (Ricoeur, 1985) argues narratives construct social subject positions and respective subject identities. The subject understands her/his personal narrative identity through narratively constructed social roles and what it means to be a good performer in those roles. Ricoeur's subject constitutes the narrative self through narrative apperception, through which the subject negotiates two identities throughout time and within a narratively constituted reality. First, the "idem" (p. 246) identity, or the same self, which is a diachronic self—repeated through space-time. Second, the "ipse" (p. 246) identity, or the new self, where the subject presently incorporates new narratives into the idem identity. My excessive weight lifting, not taking my medication, consistently shaving my hair, and not talking to my friends are coping performances and embodiments of my narrative apperception. The ipse identity is always negotiating new narratives understood through one's existing idem identity. The idem identity and ipse identity are effects of a phenomenological process, where performing in a narratively constructed reality shapes and reshapes identities, bodily performances, and experiences of self. My coping performances, which predominant medical and psychological narratives of coping would label maladaptive, were also performatives of my narrative identity, where my idem identity was pervasive, and resisted my cancer identity.

## **Narrative Uncertainty and Master Narratives of Cancer**

Narrative identity has to do with a subject's exposure to, and incorporation of, narratives and master narratives. The reflexive connection between a cancer patient's personal narrative, narrative identity, and cancer narrative discourses requires this exploration into the performing body's experiences in a narratively shaped reality. Master narratives of cancer, or privileged cancer narratives circulating public discourses, affect cancer patient experiences.

My family used to say things like, "you're so brave," or "we're going to beat this." That never really made sense to me. I was not fighting cancer. If anything, I was enduring cancer. And what does that mean for patients who died. Were they not brave enough? Did they not fight hard enough? Master cancer narratives provide structures wherein cancer patients make sense of their cancer experiences. Cancer narratives circulating in public discourse construct a hierarchy of cancer stories in which "some illness stories are more familiar than others, more welcome, more permissible—and, finally, more speakable" (Segal, 2007, pp. 13-14). For Segal,

The available structures themselves for storying illness can make and keep us ignorant about cancer. I want to add that the conventional features of the personal narrative are so well established that even those authors who try to write against the standard story often, in the end, just wind up writing it again (p. 15).

Dominant cancer narratives in public discourses contribute to a patient's narrative uncertainty by privileging particular cancer narratives (Park Fuller, 1995). The structures (e.g. binary, metaphor, metonym, and plot) undergirding privileged cancer narratives can polarize patient experiences and respective identities, leaving more uncertainty for patients who experience cancer differently from its dominant narratives in public discourses (Langellier, 1999; Mattingly & Garro, 2000; Segal, 2007; and Stacey, 1997). Scholars making similar contentions include that language, binaries, themes, and plots underlying privileged cancer narratives influence patient experiences and performances of coping (Mattingly & Garro, 2000; Park Fuller,



1995; Stacey, 1997). Cancer narratives fall under two categories, whether the patient did or did not survive (Stacey, 1997). Moreover, cancer narrative themes surround bravery and heroism. When a patient survives, stories depict the patient's "struggle against adversity" (p. 1). These narratives expose transformation as "the patient moves from victim to survivor," she or he has "faced death and . . . recognized the inevitability of human mortality" (p. 1). This theme of bravery and heroism even surfaced in cases when a patient did not survive, "the story is one of loss and pain, but also tends to be a celebration" (p. 2) of the patient's life; they fought the good fight and lost. Cancer stories often use particular language: battle, fight, beat, and survive; but, I never felt like I fought cancer.

When one's lived experience counters master narrative discourses, another type of narrative uncertainty surfaces. In fact, the military metaphor applies better to physicians, who have an active role whereas the patient has a passive role (Frank, 1995). A patient passively (while a physician actively) fights, battles, enacts war on disease in the patient's docile body. The body becomes the site for battle between the physician and the disease, not the patient. Cancer narratives using military-like language offer metaphorical transportation—if not transformation—of narrative identity. Subjects move from a position of victim of disease to the position of active agents in their cancer story. In the telling and retelling of cancer stories, patients either contribute to, or resist, the grand or master cancer narratives that shape and reshape a public's understanding of what it means to have cancer (Langellier, 1999). Personal narratives contain hidden forces in grand or master narratives and can expose the relationship between lived experiences and underlying discursive power structures (p. 129). Power exists in discursive structures and their histories, which shape identities and relative subject positions (Foucault, 1978). If discursive structures underlie narratives and dominant narratives structure

subject positions (which shape subject experiences), then narratives play a role in shaping cancer patient experiences, cancer performances, and cancer identities. Exhale.

### **Narrative Uncertainty and Personal Narratives of Cancer**

I was at my family barber shop when my mom called. She told me to come home. Like any sixteen-year-old, I told her I would be home when I got there. I have never forgotten her response. “No. You need to come home, right now. The results of your blood tests are in, and we need to go to the hospital, immediately. They have a room waiting for you.” So, I left, immediately. When I walked into the house, my sister’s door was shut; it was never shut. I could hear her muffled crying coming from behind her door. Looking back, I think she may have stuffed her face into a pillow. My mom called for me to come upstairs. As I did, I saw my dad. Our eyes briefly met, and, for the first time, I saw tears in his. He looked away. My mom asked me to sit down, but I stood. Then she said it again, “Please, sit down,” so I sat. Back then, my mom did not say please too often. She looked at me and asked, “Do you know what leukemia is?” I nodded my head and said, “Yeah. It’s cancer--right?” “Yes,” she said, “it is cancer.”

My story articulates cancer diagnosis as biographical disruption. The diagnosis marks change to my personal narrative, where my life story will fall victim to cancer. “Narrative identity takes part in the story's movement in the dialectic between order and disorder” (Ricoeur, 1985). As noted in Chapter 2, Frank’s (1995) illness narratives suggest stories depict the back and forth movement between order and disorder through three stages: pre-liminal, liminal, and post-liminal. Frank’s stages well describe the arrangement for many illness stories and somewhat fit my cancer story. However, Turner’s (1982) social drama uses four stages to describe a social group’s back and forth movement between order and disorder after a social disruption: breach, crisis, redress (liminal), and reintegration/schism. Though Turner did not intend social drama for

the biographical disruption in a personal drama, a social drama framework better describes my cancer story. Cancer symptoms (and medical visits) breach the order of a patient's body, which escalates to crisis at diagnosis. Redressive actions occur in the medical labeling of a body and its treatment and liminality ensues for the patient. Finally, if in remission/cured, the patient reintegrates into the social order as a survivor of cancer—a victor over the disease. Turner's social drama differs from personal drama but the personal drama of a cancer diagnosis becomes a type of social drama. Social and public discourses of cancer open a dimension of coping strategies through which Turner's approach helps to consider if what research labels maladaptive is really maladaptive or part of how one socially situates in or against a normalized public discourse of cancer.

### **Cancer diagnoses are speech acts**

The oncologist and I co-constructed my diagnosis in his speech act, reconstituting the convention of pediatric cancer diagnosis. A cancer diagnosis is indexical, pointing to past speech acts of diagnosis. The speech act of a cancer diagnosis is then conventional, iterable, performative, and co-created. My final diagnosis was not dramatic. The attending oncologist walked in the room and said—in the same matter of fact tone he issued my blood results. “The aspirate shows you have leukemia A.L.L. pre-b-cell. That's good; it's what we wanted.” The physician's diagnosis of my cancer was a ‘saying of something’ and a ‘doing of something’ (Austin, 1962). His diagnosis both described my type of leukemia and made a promise for future actions. I spent the next month in the pediatric hospital until oncologists had control over my illness. Once in remission, I spent nearly three more years in and out of the pediatric hospital until my completion of treatment. Outside the hospital and clinic, my cancer diagnosis socially marked my body as different, as unhealthy, as other.

Cancer diagnoses are narrative speech acts. Not only does a cancer diagnosis set forth a narrative journey for the patient, but also the act of telling a cancer story along with collective cancer stories are second-order speech acts (Langellier, 1989) that do something in the world. A cancer story is contingent upon the speech act of diagnosis. Additionally, when telling a cancer story, the story teller is not just saying something, she or he is doing something. The story teller has an intentional meaning for telling the story (Mattingly & Garro, 2000). The story carries this meaning, and the context moderates this meaning through the individual histories of its audience. The audience's uptake of the story results in both intentional and unintentional meanings indicating the cultural complexities involved with the effects of telling a cancer story. Narratives contain illocutionary<sup>46</sup> forces and meanings, having perlocutionary<sup>47</sup> effects on its receivers.

Personal narratives, like my autoethnographic tale, then, too, are speech acts. Diagnosis is common in cancer narratives and stories, like mine, “provide a means for conveying the biographical disruption caused by illness . . . Rather than stories about illness, such accounts are better characterized as being about a life disrupted by illness” (Garro & Mattingly, 2000, p. 27). Disrupting life is a theme in cancer narratives and can act as the catalyst for patient transitions and/or transformations—patients must move from victim to victor, from disorder to order, from healthy to unhealthy. I illuminate identity disruption to show my diagnosis was more than an inscription and more than a cancer story. My cancer diagnosis was a speech act, which had a

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<sup>46</sup> For Austin (1962), the illocutionary act is the ‘act in saying something’ through which the act possesses forces in the intended meaning in the act.

<sup>47</sup> For Austin (1962), the perlocutionary act is the effect the illocution has on the person receiving the utterance. This includes effects from the utterer's intended meaning and unintended meaning in the utterance.

perlocutionary effect of narrative liminality. As I encounter a new and uncertain cancer identity, my coping performances had to negotiate two narrative positions.

### **Narrative liminality as a perlocutionary effect**

Time stopped for me after I heard the word cancer. I knew my mom was still talking, but I was no longer listening. I could not think. I could not process. I was stuck in that moment; I was stuck in that word—cancer. I vaguely remember my mom telling me that they do not know for sure, that they still need to do some tests, and that we should hope for the best. But, my sixteen-year-old mind filled with the uncertainty about cancer and all its connotative meanings: chemo, radiation, life, death, pain, suffering, needles, doctors, hospitals, and hair loss. That word, cancer, it inscribed me; it impacted me; it changed me, immediately. Exhale. Inhale.

Hold. Hold. Hold.

Liminality is a result of a cancer diagnosis. Anthropology has looked at identity as culturally marked through an individual's performances of social rites and rituals (Turner, 1982). Disruptions of identity result from transitioning between "two narrative moments . . . bounded by clear cultural markers that separate such occasions from the ordinary routines of everyday life" (Mattingly, 2000, p. 181). Turner (1982) indicated these transitional moments as liminal; they exist in the threshold between two places, or the undefined positions between two narratively defined positions. The liminal effect of diagnosis situates between the disruption of a patient's healthy identity and the incorporation of a new unhealthy identity. A diagnosis of "cancer therefore emerge[s] in the context of a larger social framework" (Hunt, 2000, p. 91).

The disordering of narrative identity contributes to patient uncertainty. A narrative paradigm reframes uncertainty from a subject's unknown information about the disease to a subject's performative negotiation of an unknown narrative identity as a cancer patient. Patients

who tell their diagnosis stories “articulate and mediate disruption” (Hunt, 2000, p. 89). The liminal patient must occupy new and uncertain spaces between narratives while performing new actions and new rituals as they narratively transition into identifying as a cancer patient. “In [this] experience, medical space can coincide with social space, or, rather, traverse it and wholly penetrate it” (Foucault, 1973, p. 31). My first morning in the hospital, I awoke to two men dressed in scrubs. One was moving around my IV, while unplugging some machines; the other was putting up the safety railings on my bed. They were quite chipper while they were doing this, and I was in no mood to appreciate their good mood, or the early wake up call. They were talking about a football game as they rolled me out of the room and into the hallway. One of the men asked me, “So who is your team?” I said, “I don’t have a team. I don’t watch football.” My response quieted their conversation, making for a much more uncomfortable ride. Exhale. Hold.

One might view my transition between identities as merging narratives and performatives, wherein subjects manage uncertainties associated with cancer identity through its performance inside and outside of hospital spaces. It is both the “betwixt” and the “between” that make the liminal patient. My response, “I don’t have a team. I don’t watch football,” was an avoidance of social convention—small talk. Had the conversation taken place a week earlier or a month later, I would have exchanged in conversation. I was, and usually am, eager to engage in small talk. The liminal subject situates between two narratively constructed positions. A performative process moves liminal subjects from the position of identity disruption to its cancer narrative reconstruction. Liminality reframes information seeking and narrative sense making as a matter of an uncertain cancer narrative identity, where my embodiment of narrative apperception can signify changes to my narrative identity, its uncertainty and uncontrollability.

## **Performatives and Performativity**

I am not sure when I started to feel like a cancer patient. I guess it was when I began to look and act like a cancer patient: no hair, pasty sallow skin, sunken eyes, and a doughy-like body, along with the routines from being a patient in and out of the pediatric hospital, cancer clinics, and laboratories. I never actually felt like a cancer patient until I was several months into treatment. The funny thing is, I was in remission from cancer when I felt like that. I received chemo for nearly three years after I was in remission. Inhale. Exhale. Inhale. Exhale. Inhale.

The performative turn privileged the performing body as constituting identities. Butler's (1988) version of performativity syntactically positioned the performing body as both subject and object, where performing bodies have reciprocal relationships, always and already acting upon one another. As a human subject, the performing body creates actions that 'do something in the world.' In turn, and as object, the social world acts upon the performing body. In my body's incorporation of my cancer patient experiences, my bodily performances negotiated my cancerous body and its connection to text and meaning in both the social world and the world of medicine. In Butler's (1988) version of performativity, a subject's identity is a "performative accomplishment" (p. 520). instituted, constituted, and reconstituted through the embodiment of stylized, repeatable, and citational acts. Diagnosis instigated a rapidly changing identity, which my coping performances resisted.

The citationality of the performative act, makes present a performance that was absent, meaning the performative act was on the scene before one was there. Butler maintained bodies and their performances structure present norms and identities through performatives, which are reflexively bound to culture, its language, narratives, and histories. For Butler (1988), hegemonic forces embed within performative acts, circumscribing subject performances to re-present

dominant performances. She revealed an inessential subject, a sociohistorical and linguistic conflation of the body and its performative attributes. Hence, particular performatives signify particular bodies, and particular bodies signify particular performatives, all of which produce social culture and its normative identities. The construct of health as normal affected my coping.

### **Performing Narrative Identity**

Sociocultural identities are narrative and “performative accomplishments” (Butler, 1988, p. 520) that produce and reproduce sociocultural realities. For Ricoeur (1985), identities are narrative accomplishments through which the embodiment of the story constructs and reconstructs social positions and subsequent performances and performatives. I have suggested a subject performs narrative identity in a narratively constructed reality. Performances and performatives reflexively constitute narrative identities and narrative realities, which in turn shape and reshape positionalities and a subject’s performances and performatives. Though tautological, this circularity foregrounds the reflexive role narratives and performatives play in shaping and reshaping consciousness and bodily performances. This is maybe why I did not feel like a cancer patient until long after I started performing the role of cancer patient? The performing body becomes a semiotic matter (Worthen, 1995), a symbolic sign situated as both signifier and signified. Coping performances, then, are more than significations of an appraisal seeking to manage the uncontrollability and/or uncertainty of cancer, coping performances are reflexive performative acts situated in the narrative self, understood as one relates to others in narrative contexts.

The pediatric hospital had toys and games everywhere. The walls had bright cartoon designs and toys built into them. The TVs were usually playing cartoons or kid shows, like Barney. So, many of the children would sit and play various games all over the floor. The



magazines in the waiting room mostly targeted parents. I remember *Better Homes and Gardens*, *Parenting*, *Health*, *Nutrition*, and the occasional fashion magazine. My mom and I used to sit in the two chairs near the front desk. They were furthest from the play area, where most of the other patients were young—under ten years of age. Pediatric hospitals can do more than set patient stories. Place organizes space through which subjects live and move through “representation[s] designed to formalize the structure of a component of experience” (de Certeau, 1984, p. 2). The design of space and place governs spatial practices, authorizing performatives attributed to conventional places, circumscribing other possible performances for performers. Pediatric hospitals and clinics then communicate to patients, wherein the spatial design of pediatric spaces ‘formalizes particular experiences’ for pediatric patients. However, the term pediatric cancer often connotes a younger child. This connotation is a sociocultural effect from the construction of pediatric cancer through dominant pediatric narratives and pediatric representations circulating public, personal and medical discourses. The adolescent cancer patient is an invisible pediatric patient, nearly absent from the public imaginary of pediatric cancer.

### **For a Narrative and Performative Model of Coping with Cancer**

I stare at my pack of cigarettes. I have wanted one all morning, but the dissonance is killing me. For several weeks, I have had increasing lumbar pain, and today the thought occurred to me: I could have a cancerous tumor in my lower spine. Although my back pain is likely from a slipped disc, cancer’s return is always a fear. Inhale. Inhale. Inhale. Despite its absence in my body, cancer continues to be present in my mind. The perlocutionary effect from the speech act of my cancer diagnosis was liminality, I was, and perhaps am, ‘betwixt and between’ two narrative structures: my biographical narrative and a cancer patient narrative. As newly

diagnosed patients incorporate cancer experiences, patients consciously and/or unconsciously embody narrative identity, or an ongoing matter of narrative apperception.

Apperception suggests the conscious negotiates new bodily experiences against memories of past experiences. Narrative identity, a process of narrative apperception, is the incorporation and negotiation of new narratives with one's existing narrative self. Cancer patient stories articulate bodily experiences situated in or against dominant cancer narratives. The free association of language, themes, binaries, plots, used when patients tell cancer stories can expose a subject's narrative apperception. Analyzing narrative structures embedded in cancer patient stories reveals the reflexivity among bodily experiences, personal narratives, master narratives, and narrative identities. Master narratives of cancer and their structures can become inescapably repeatable in personal narratives of cancer (Segal, 2007), which always possess narrative elements in master narratives (Langellier, 1999). To put it simply, how we talk about, and how we story, cancer in public, personal, and medical discourses can affect how we experience cancer, how we make sense of cancer, and how we story our own cancer experiences.

To repeat the multi-theoretical model suggested earlier that I will apply in the following chapter: (1) a cancer diagnosis and its narratives are language in action; (2) there is an uncertain and narrative liminality of all cancer patients, and of adolescent patients in particular; and, (3) that narratives and their discursive structures create performed actions, narratives, and narrative identities as much as they are created by performed actions, narratives, and narrative identities. Coping is then a performed (re)action to a stressor and a performative act reflexively tethered to narratives. In the act of telling a cancer story, the storyteller constitutes and embodies a narrative identity. The incorporation of, or resistance to, dominant cancer narratives may reveal further insight to coping with cancer's uncertain and uncontrollable identity. For example, my rejection

of military-like metaphors rejected a dominant element in a cancer narrative, but in my cancer experiences, I never felt like I fought or battled anything. If anything, I felt like I *endured* cancer.

I tilt my head down and to the right,

Bringing a cigarette to my lips.

I raise the lighter to reach the cigarette's tip,

Rolling my thumb to spark its flint.

Deep inhale.

Slow exhale.

Repeat.

**CHAPTER 5**  
**“OUR CANCER STORY:”**  
**AN ETHNOGRAPHY OF ADOLESCENT CANCER VIDEOS**

I sit down on my gray couch. I stare at the screen on my laptop; then, I type the following words into Google’s® search engine: “teenage,” “cancer,” “story.” Search results show over 71,600 videos, a row of pictures with video titles run down my screen. I look at the top result. I have seen that video. In fact, I have seen many of these videos. I continue to scroll, until I see, “My Cancer Story.”

Inhale. Exhale.

In this chapter, I use critical reflexive ethnography to explore adolescent cancer patient stories posted online for public audiences. As I bear witness to each patient’s story, I reflexively engage and critically analyze the patient’s performed act of storying cancer. I foreground my position as an emerging scholar who had adolescent cancer, with which I continue to cope. I also note, I am a CIS gendered, heterosexual adult male of Mexican and Irish heritage. When viewing these videos, I engage the patients’ bodies and their stories through my own bodily experiences, bodily actions, memories, and thoughts, adding fragments from my own cancer story. I include my present coping experiences as a survivor who studies adolescent cancer and who at times finds this research very difficult to do.

I argue the act of storying personal cancer is an act of coping with a cancer identity, an act constituted by and through a narrative and performative subject. As discussed in chapter four, the narrative and performative turns suggest sociocultural narratives and performatives shape subjects as much as subjects shape sociocultural narratives and performatives. From a narrative perspective, subjects are born into a reality previously created from systems of stories and shared narrative elements (e.g. plot, role, language, et cetera). Subjects constitute identities by making

sense of themselves, others, and their realities through those shared systems of meaning (Fisher, 1984; Ricoeur, 1985; Bruner, 1991). The performative turn supplements a narrative framework by its focus on the body and how bodily acts produce and reproduce (inter)subjective identities, and how performed actions (re)materialize sociocultural realities (Butler, 1988). Everyday life performances move the individual through the cancer story. As reviewed in chapter two, Frank's (1995) illness narratives articulate the body's dialectical movement between healthy and unhealthy, between normal and other. Patient stories either waive or reclaim the cancer body. The telling of a personal cancer story becomes a matter of coping with one's cancer narrative identity, as well as a window into how patients cope with cancer's uncontrollability and uncertainty through the act of storying restitution, chaos, and quest narratives. The metaphoric and metonymic language used or not used in the story can add another layer to coping within one's story. I supplement Frank's narrative analysis with performance analytics drawn from Victor Turner. These terms help to address not only what the narratives say, but the social actions that they perform. In addition, the physical embodiment of telling a cancer story online is a performance for public audiences. The act of storytelling narrates, not only organizes, frames, and edits personal cancer experiences, but is also a presentation of self. In the performance of telling one's cancer story, the storyteller constitutes her cancer (narrative) identity.

### **Critical, Self-Reflexive, and Performative Ethnography**

Inhale.

It is just after 7AM, and I already feel anxious.

Exhale.

I pace around my apartment for several minutes.

Inhale.

I want a cigarette.

Exhale. Inhale. Exhale.

“Performative autoethnography is a critically reflexive narrative representing the researcher’s personal and political intersections/engagements/negotiations with others in culture/history/society” (Spry, 2011, p. 53). As I mentioned in Chapter 3, I prefer autoethnography as an exploratory method of enquiry partly because it is non-intrusive. By contextualizing the sociocultural position of the researcher, critical self-reflexive autoethnographies illuminate researcher subjectivities and cultural context through personal experience(s) (Madison, 2012). Critically reflexive autoethnographic work, however, does more than focus on the researcher, it places attention on sociocultural effects constituting othered bodies (Spry, 2016). In my approach, I apply a critically self-reflexive orientation (Alexander, 2006) toward adolescent cancer patients. I focus on cancer’s sociocultural effects narratively entrenched in cancer stories and a patient’s presentation of self through the physical embodiment when telling one’s personal cancer story.

In the following analysis, I situate videos of cancer stories in conversation with my own cancer story. I explore adolescent cancer, and my life after cancer, by reflexively engaging and critically analyzing four separate videos posted online and titled, “My Cancer Story.” I allow my interest in videos titled, “My Cancer Story” as well as my interest in the aesthetic of a video’s icon to determine my video selection. Three videos (*Ovarian Cancer*, *Hodgkin’s Lymphoma*, and *Wilms Tumor*) are adolescent females diagnosed approximately three months prior to posting the video online, one of whom (*Wilms Tumor*) fell from remission several times earlier and is, again, a cancer patient. The fourth video is a nineteen-year-old female survivor of adolescent cancer (*Survivor of Ovarian Cancer*). Each teenager uploaded the video online for public audiences and

via a personal account. “When the self looks into the camera, it hopes for the gift of its gaze to be returned” (Richter, 2002, p. 227). I view the interplay between trace and aura and the shifting proximity of presence from each performed cancer story. In addition, I reflexively engage the patient’s story, allowing the patient’s body, bodily acts, narrative, and language to affect my present body, bodily acts, thoughts, and memories. I poetically write my present coping experiences when viewing these videos, adding fragments of my own cancer story when triggered by an adolescent’s story and/or storytelling. A reflexive audiencing of their videos, helps to re-embodiment their online narratives. I seek to record our co-presence, a story of we, not just me. When placing our stories together, they critically expose performative forces shaping how we see ourselves in our cancer story. The lens of performance adds to the analysis what narrative as text misses.

I offer three general areas that relate the stories and storytelling to coping with cancer’s identity. First, in telling one’s cancer story, an adolescent patient details the body’s dialectical movement from healthy to unhealthy. Frank’s (1995) illness narratives help to expose shared narrative elements and an (un)controllability underlying passive and active illness stories. Second, in telling one’s cancer story, an adolescent patient uses language consistent with, or absent of, language associated with cancer’s military metaphor. The usage of this metaphor can transport a patient as an active or passive agent into the cancer story. Third, in performing a personal cancer story, an adolescent patient’s presentation of self may embrace or resist the cancer body, wherein some patients enact resistance of the cancer body by covering cancer signifiers to pass for normal. Others may embrace cancer’s non-normal body, resisting a healthy-bodied aesthetic.

## **From Healthy to Unhealthy, Dialectically Narrating Cancer**

In this first section, I apply the narrative and performative model from chapter four to unpack how these adolescent cancer patients constitute their cancer identities when telling their personal cancer story. The act of storytelling organizes personal experiences. When telling a personal cancer story, a storyteller pieces together fragments of cancer experiences and non-cancer experiences, in which the storyteller performs one's cancer narrative identity. I first explore the underlying narrative structures in these cancer stories by separating this section of the analysis into two subsections: (1) narrating cancer through Frank's (1995) illness narratives, where I explore each story's usage of Frank's restitution, chaos, and quest narratives, as well as how these stories expose a narrative (un)controllability; and, (2) Turner's (1982) theories on drama and liminality can provide a narrative structure for these cancer stories that expand upon Frank's illness narratives by offering a more complex structure to the narrative, while connecting liminality to performance and identity. The performance of telling a cancer story makes these narratives embodied social actions rather than merely abstract social texts. Either the liminal identities in redress can be (re)incorporated to the normal social fabric of everyday life or schismatic identities can claim their schism from normality, embracing their liminal identities and their status as neither belonging nor not belonging to the fabric of "normal" everyday life.

### **Narrating Cancer through Frank's Illness Narratives**

As noted in chapter two, patients often weave various narratives together when telling an illness story. Frank (1995) detailed three types of illness narratives: the restitution narrative, the chaos narrative, and the quest narrative. For Frank, illness stories narrate the body's movement from healthy to unhealthy and then back to healthy. However, Frank considers the chaos narrative, "the anti-narrative" (p. 98), a narrative without structure, having no order, so rare that



the chaos narrative does not exist on its own. Patients articulate chaos when recalling experiences of being in the liminality of antistructure. The restitution and the quest narratives both describe a patient's journey through liminality in three stages: pre-liminal, liminal, and post-liminal.

The restitution and the quest narrative place the chaos and disorder associated with being liminal within their narrative frameworks. Restitution and quest narratives have a biomedical telos of healthy, wherein health is order, and curing illness not only restores health to a patient's life, but also returns a patient to normal everyday routines. When detailing restitution and quest narratives, patients narrate themselves as either passive or active agents in restoring their health. A patient's passive and/or active role when telling cancer experiences can expose the uncertainty and (un)controllability of the patient's narrative, which makes the act of storying cancer a matter of coping with cancer's chaos in liminality. Further, liminal selves grasp at strategies to try to create a permanent schism or (re)integration to everyday life. Through schism or reintegration, these texts are social actions. In this section, I explore each video through the lens of Frank's (1995) illness narratives: restitution, chaos, and quest. Frank warns not to categorize an illness story as a single narrative type because stories often utilize all three illness narratives. Thus, I separate each video through underlying liminal stages of Frank's illness narratives: pre-liminal, liminal, and post-liminal.

### **Video 1—Ovarian Cancer: Passively Telling A Restitution Narrative**

I see a video link with the title, "My Cancer Story: How I found out I had Ovarian Cancer." The patient is fifteen-years-old and has individually uploaded her video, but under an anonymous name. I see my mother's face in the girl, and my head fills with pictures of my mom when she was young. I wonder if the patient is also Mexican-American. I think of Paula. She was

my first hospital roommate, a six-month-old Mexican-American baby, born with, and eventually died from, leukemia. I then think of Junior, my second hospital roommate; he also had leukemia.

Junior was an 8-year-old Mexican-American boy with Down Syndrome. He cried often.

Inhale. Exhale.

I press the link and the video plays.

The pre-liminal stage—restitution's (un)controllable uncertainty unfolds

Hi, this is my cancer story, and how I was diagnosed with ovarian cancer. So, let's just jump right into it. Um, how I first found out. Sooo, I waaassssss laying down, on my laptop and I noticed this really weird large lump in my lower left abdomen. And, I told my mother about it. And, she's like, well, does it hurt? And, I was like there's no pain, eh-it's just, it's just uncomfortable because it feels like, like, it's gonna pop. I had to like maneuver my body around this mass in me, eh-it was weird I tried not to bend in certain ways. So, um, she was like okay, we'll go see a doctor and have'em check it out. Soooo, we went to the doctor's, and she felt, she felt, does this hurt, does this hurt, does this hurt? And, I was like no, it's just weird. She said, well, it could be a fibroid, so we're gonna have you set for an ultrasound and we'll call you back when your cells come in.

Inhale. Hold.

My cancer started with symptoms of fatigue, loss of appetite, joint pain, and pervasive headaches. I told my mother, who first thought I had overextended myself with school, work, sports, social life, et cetera. My joint pain grew worse and eventually incapacitated my movement and I soon began to sleep all day. My mom decided to take me to our pediatrician after I nearly slept an entire weekend. The pediatrician told my mom it looked serious, so he ordered blood tests. Like the patient in the above passage, here I begin my story with symptoms. The restitution narrative sequentially organizes events in the story, using a chronological narrative (Frank, 1995). The storyteller often begins the story in the pre-liminal stage before, or when, first noticing symptoms. A patient's symptoms then move the patient deeper in the chaos associated with the liminal world of medicine and being and becoming a cancer patient. The storyteller must embark on a passive journey of restitution, wherein the narrative chronologically

guides the patient through an underlying dialectic from healthy to unhealthy, wherein the goal of this narrative is to restore the body back to health. The restitution narrative is the dominant biomedical narrative in which medical authorities are the active agents guiding the outcome of the patient's story. Patients often become passive in controlling the story and its outcome.

The patient in the above passage starts her story by telling and embodying her memory of the lump she "feels" in her stomach, and the restrictions the lump caused when maneuvering her body. She physically wiggles around and scrunches her face as she describes the lump. After telling her mother, the two go to the family doctor, in which the storyteller's passive role of being a patient starts. When she describes her physician touching her lump, she switches her narration from the historical present "feels" to the past tense, "felt," adding another passive layer to articulating this experience. When her physician orders an ultrasound, the patient becomes a passive object to the medical gaze and her physician becomes the active agent in her cancer story. Choices made by medical authorities direct her movement through the restitution narrative.

Soooo, go and get an ultrasound, and I-I've never had one before, so it was weird. They get like the gel out and started around my belly. Uh, it's so cold. And, um, I was just, I wasn't really nervous. I was just, like, looking at the screen, going, oh look at—there are my kidneys. Oh, look at—that's a liver, oh, look at all my organs. Yeah, that's how I, kind of like, I wasn't thinking it was going to be anything too serious. And, then, got a call. I don't know if it was that day or the next day, but we got a call that they, I, had to go get a cat scan. And, that's when I was like, whoa, this might be pretty serious.

Inhale. Hold.

After evaluating my symptoms, my pediatrician said it might be serious. The severity and acuteness of my joint pain made him think that I had a type of child's arthritis. Unlike the above patient, my test was not new to me, but I still experienced a great deal of uncertainty in what was happening to my body, and a potential future with a crippling arthritis, or something else unknown. In her depiction, the patient recalls her experience with having an ultrasound by

articulating and embodying memories of uncertainty. The patient smiles throughout her story, but she quickly stops to say, in a serious tone, “I-I’ve never had one before, so it was weird.” The patient begins to gesture with her hands to describe the diagnostician taking out the gel and applying it to her “belly.” Her facial expressions become exaggerated as she further details her experience. The patient leans back, her eyes widen, raising her eyebrows and she says in a strange voice to the camera, “it’s so cold.” She looks stunned. She continues in the historical present tense and past progressive tense but begins to shift to a passive disembodied experience when she recounts viewing her organs on a screen. “And, um, I was just, I wasn’t really nervous. I was just like looking at the screen, going, oh look at, there are my kidneys. Oh, look at, that’s a liver, oh, look at all my organs. Though the ultrasound is an uncertain experience, she “wasn’t thinking it was going to be anything” serious until her physician called and had ordered a CAT Scan. Though my and the patient’s narratives are still in the pre-liminal stage, our growing uncertainties associated with illness move us closer to the liminal stage.

So, I got the Cat Scan, and, ew, they made me drink this, um, this weight smoothie—ish. It was awful. There was banana flavor, vanilla flavor, and, uh, berry flavor, um, I don’t know if it was berry, but yeah you had to drink 32 ounces, which was like, four eight-ounce cups, and it was nasty. And you had to drink a cup every five minutes, er, excuse me every 15 minutes. And, for like two cups I was okay. By third cup, I was, I was gagging. Trying to drink through a straw. No, it’s, it’s just awful. And, then when you are finally done, when you’re finally done drinking those four cups, and you go into the room with, the, the, the woo—too, the little donut thing and, and, and you’re like you’re so happy, cuz you’re like yay! Yes! Thank you! Thank the Lord. I don’t have to drink anymore of this crap. And, then someone comes in and says, yeah you just, you just need to drink this, this, this cup now. And, I’m like, NOOO!! Are you serious? Another cup? I’m like agh, ugh, I just chugged it, and it was—agh—awful. And um it wasn’t even like thin, it was like thick-ish, agh, ugh, it was awful, but, um. So, I got the cat scan, and, they called that night saying there’s a large mass. We don’t know what it is, but there’s a large mass in your abdomen, and you have to get it surgically removed.

Inhale. Hold.

I remember those “nasty” drinks and the thick consistency of granulated particles moving down my throat when I would swallow, what felt like, wet sand. After I finished drinking a shake, I could still taste the pseudo vanilla flavor when my tongue cleaned particles of powder stuck to my teeth and gums. The experience was unpleasant, and I find myself making faces while writing this. The patient’s voice and physical embodiment expresses her passive experience drinking the “shake.” She squints and the muscles around her cheek bones create a puckered expression on her face as she says, “they made me drink this, um, this weight smoothie. It was awful.” When the patient articulates her passive experience, she refers to an anonymous “they,” or the medical authority who “made” her drink the shake. Later in the passage, she, again, refers to an anonymous medical authority, “someone comes in and says, yeah, you just, you just need to drink this, this, this cup now.” Her eyes and mouth open wide and then she slowly says, “no.” The patient leans her head back and gestures to mimic chugging a drink as she makes gagging noises.

Towards the end of the passage, she receives a phone call with results of her CAT Scan, which passively drives the storyteller through her cancer story and closer to the liminal stage in the restitution narrative. The phone call in the patient’s passage resonates with me. A phone call is also part of my story. As I detailed in chapter four, there was an unexplainable liminal moment when my mom called me at the barbershop to tell me my pediatrician called with the results of my blood test, and we had to go to the hospital immediately. Like my cancer story, the phone call in this patient’s story is a significant moment of liminality. She passively moves into the threshold between two worlds: healthy and unhealthy. Medical authorities must remove the unknown mass in her belly to control the uncertain chaos of her illness, which directs her story.

Liminal Stage—restitution's (un)controllable uncertainty is chaotic

Okay, now getting surgery, never been to the hospital, never been, done anything before, I think I had blood drawn once in my life and that's about it. And, now, I'm just like going through all these things, now I'm getting surgery. It was crazy. So, I went a couple days after that, my CAT Scan, to talk to my surgeon. And, he was telling me how I have a teratoma tumor, and by looking at the CAT Scan that looks like it's attached to my left ovary, which it was. And, he was talking about how there could be possibility that there was another tumor growing in my right ovary. And, it just, he was just, this's funny though, cuz teratoma tumors are the kind of tumors that can grow hair and like teeth and stuff. And, he was telling me how it looked like there was like a tooth and some kind of tooth material. I was like, oh god it was like a creature thing growing in me. And, um, I named it Fred. The one on my left ovary his name is Fred the tumor, And, and, so, yeah, he was telling me about how he was going to try to remove this tumor and the chance of this one tumor being cancerous was 1 out of 10. So, he said, don't worry about it. I still was worrying about it. I mean, 10% chance that's too high. He's like it'll be okay. You may not be able to have children. We don't know. And, we'll just find out if there's a second tumor when we go into surgery.

Inhale. Hold.

Unlike the patient in this story, I had experienced various medical situations by the time physicians started to diagnose me with cancer. My asthma and allergies kept me in medical settings during my childhood. One time, my asthma was so bad I spent Christmas in the hospital and inside an air tent. I also remember spending many Saturdays waiting in a clinic for allergy shots. By the time I was sixteen, my asthma and allergies had improved, but I had experienced a host of other things, in which I became familiar with medical settings, such as several broken bones, operations, stitches, and staples. However, I still had a high degree of uncertainty surrounding the results of my blood tests. My uncertainty started with the phone call at the barbershop; it was the moment that began my separation from my daily life and its routines. Soon, the diagnosis would initiate the uncontrollability to my story. The teenager in this cancer story states she only had her “blood drawn once,” revealing her inexperience in medical settings. She talks about her surgical consultation, in which she will have surgery to remove her tumor. This consultation is a noteworthy moment of liminality and its uncertainty. Like the phone call I

received at the barbershop, from this point forward, medical authorities will separate the patient from her daily life and its routines. The results of her surgery will determine the rest of her story. She is liminal, 'betwixt and between' her old narrative self and a new uncertain narrative self.

In her liminality, we see chaotic parts emerge in her story. Patients may texture chaos in a restitution narrative; however, people rarely tell a true chaos narrative (Frank, 1995). In fact, a true chaos narrative would break the chronological telling of the restitution narrative along with breaking temporality of action in the story. Plots in a chaos narrative are nonsensical and can shift between past, present, and future, wherein patients often tell past and future events in the present tense. The patient with ovarian cancer continues a linear and sequential plot; however, throughout her story she shifts between the historical present, the present, and the past tense. For example, when she says, "And, now, I'm just like going through all these things, now I'm getting surgery." The patient has had surgery, she will discuss the results in the next passage, yet she maintains present participles here, almost re-living the story as she tells it.

Despite a chaotic temporal dimension to her verb tense through her shifting between imperfect active and imperfect passive tenses, past tense and present tense and/or past progressive tense, the patient's story is consistent with the chronological telling of restitution and the passive role of being a patient. Medical figures in her story occupy the role as active agents. Physicians, nurses, phlebotomists, and more control the movement of the storyteller through her own story. This is evident in the above passage when she notes her surgeon labels her mass as a "teratoma tumor." The patient passively describes the tumor as if it is separate of her body, "it was attached" to her ovary rather than produced by her. The patient continues to distance herself from her tumor when saying it "was like a creature thing growing in [her]." The patient takes an active role in her story when she names her creature-like tumor, "Fred," further separating the

tumor from herself. In describing a creature-like tumor with hair and teeth, the removal of her tumor becomes desirable. In fact, the name “teratoma” means monstrous tumor in Greek (Chang et al., 2007). When she describes when her surgeon indicates to her that the tumor might be cancerous, the patient details her movement deeper into liminality and its chaos. She closes her eyes and looks off camera when she learns of cancer, and again when the physician mentions a possible second tumor. “He's like, it'll to be okay. You may not be able to have children. We don't know.” In this uncertainty, she is stuck between her old narrative self, and a new narrative self as a patient with a teratoma tumor. The patient has entered liminality and its chaotic narrative with an uncertain futurity, a life with the possibility of cancer and the possibility of not bearing children.

But, um, so I got the surgery. And, it turns out there was a second tumor who I fondly named Fred Jr. I couldn't think of a better name. I wasn't expecting to have a second tumor and we didn't know if it was they were cancerous, or if one of them's cancerous or not, until we got them a piece of them sent to the biopsy or whatever. I did I didn't get to see the tumors in person but I did get my surgeon to take a picture of it and I have him send it on the computer, I'm really excited about that. And, so I stayed in the hospital, and I've got the surgery on August 6th of 2012 and then on August 16th I was diagnosed with ovarian cancer stage 1C, yeah 1C, which means that they're cancerous tumors attached to both of my ovaries. And, they were shocked. Because I- I was shocked, my mom was shocked, everybody was shocked—I think they were, the main reason they were shocked is because I'm fifteen. And, typically ovarian cancer is found in, you know, older woman, not fifteen-year-olds. So, that was shocking.

Inhale. Hold.

In chapter 4, I describe the liminality I experienced when I entered the pediatric hospital. Though more blood tests indicated I had leukemia, the type of leukemia was uncertain until I had a bone marrow aspirate. The type is important, there are better and worse types of leukemia. I had hoped, and was fortunate to have, Acute Lymphocytic Leukemia (ALL) type Pre-B Cell, which statistically had higher rates of survivorship compared to other types such as ALL T-Cell. In fact, the oncologists expected I would have T-Cell because it was/is more common among



teenagers. The patient in the above passage only had a ten percent chance of cancer. However, the patient describes having an additional tumor in which both tumors are cancerous, making her story more chaotic. “They were shocked. Because I-I was shocked, my mom was shocked, everybody was shocked—I think they were, the main reason they were shocked is because I’m fifteen.” The chaos narrative emerges when patient’s articulate unpredictable experiences of illness and lived fears associated with suffering and/or death. In the above passage, the patient’s story contradicts the physician’s prediction of her 10% likelihood of having cancer. This experience explicates the physician’s uncontrollability to predict her outcome. In this liminal moment, uncertainty and its uncontrollability prevail, neither the patient nor the physician can control the health outcome, which is the goal of the restitution narrative.

So, but, so I get, eh-eh-eh-too-eh-too-poo-said [Etoposide], and aah-teh-van, [Ativan], I think that's what they're called? No. Ativan is a med, that's lorazepam (a generic of Ativan). Ativan's the name for lorazepam, which is a med that I take. Oh. Okay. Etoposide, and there's this other chemo I'm getting. And, um as far as cancers and like side effects go, I haven't really been feeling any so that's good. And, um I just wanna, I only have three or four treatments. I haven't gone to school um since the first, the whole first trimester, so I am excited to be able to go back. And, um I just if you have cancer, you know, you can do it! You can kick cancer ass! You can do it! Oh God I'm weird.

Inhale. Hold.

Methotrexate, cytosine arabinoside, daunorubicin, vincristine, dexamethasone, and a host of other chemicals (chemo), procedures, conventions, and physiological effects were all new medical language and practices I learned while having cancer. The uncertainties associated with medical language, health information, health practices, and health concepts pertinent to the treatment of my body add another layer to the chaotic disordering of the life I had before cancer. As discussed in chapter two, the uncertainty of health information is a matter of coping, one often examined through a patient’s information seeking behavior. However, evident in the patient’s story, she contextualizes her uncertainty of medical language through its effects, or lack

thereof, on her body. Her inability to pronounce the names of chemicals seem less a concern for her rather than her claim of little to no side effects from treatment. From these positive reactions to chemo therapy, her story moves through the narrative's liminal stage and towards the post-liminal, or restitution. The patient looks forward to her last "three or four treatments," which she associates with her return to school and thus a return to her life before cancer. Though patients have a passive role in the restitution narrative, and thus do not control the outcome of their cancer stories, the goal of restitution affords patients a predictable narrative with the expectation of a positive health outcome. The patient in the above passage has not finished treatment but sees her future self without cancer. In this futurity, she takes control of her story when she offers hope for other cancer patients, "if you have cancer, you know, you can do it! You can kick cancer ass!" Her language exposes an active control over her restitution narrative, as if she kicked cancer's ass rather than endured cancer while physicians treated her with medicine. "Kicking cancer's ass" creates an agonistic relationship between cancer and the patient, and for the first time in her story, she takes the role of patient as hero in her cancer story, rather than the victim.

### **Video 2—Hodgkin's Lymphoma: Actively Telling A Restitution Narrative**

I sit down on my gray couch. I set my coffee mug on the table, my fourth cup today. I bring up my Google search and my eyes focus on a video titled: "My Cancer Story: How I Found Out I Had Hodgkin's Lymphoma." I look at her last name, it is Latin in origin, and her skin is a particular sallow reminding me of my grandmother. I wonder why I keep clicking on Latin videos. I think of the patient's diagnosis: Hodgkin's lymphoma. Memories of my cousin Jeannette flash through my mind. Jeannette had Hodgkin's lymphoma since she was young. I always wondered if her parents named her after my mom—though they spell their names different. Jeannette was technically not my cousin. My parents often introduced good friends as

aunts and uncles, whose children we referred to as cousins. Physicians diagnosed Jeannette with Hodgkin's Lymphoma in early adolescence. Since her original diagnosis, she went in and out of remission a few times. The last time I saw her, I was sixteen years old, and she was fifteen. At the time, she was in remission. I would receive my cancer diagnosis several months later. Soon after my diagnosis, Jeannette would fall from remission.

Inhale. Exhale.

She and I had cancer at the same time.

Sometimes, she and I wrote one another.

She would never return to remission.

Inhale. Hold. Hold. Hold.

I click the video link and it plays. First, there is a black screen, next, flashing stars quickly appear as the girl's full name fades into large white bubbly letters. Then her name turns back into flashing stars, fading into black along with the background, revealing a fifteen-year-old girl with a smile taking up most of her face. As she looks at the camera, she speaks, in what sounds like a thick New York accent. Bronx, I think? She is contagiously boisterous and confident. I find myself immediately liking her.

The pre-liminal stage—Quest takes control over restitution and cancer's uncertainty

Hi guys. This is my cancer story . . . Um, this started, well, I found out—I diagnosed myself—thank you very much. Um, I-I didn't really notice a lump, I already knew I had it there. But, you know, I was being extra dramatic that day, and, so I told my mom, how there's a lump, right there, and, she was, uh, and I was like oh that's cancer, [ahem] and that's cancer. And, then she was like, No it's not! You don't have cancer! That doesn't run in my family. And, she was talking all of that, no you don't have cancer stuff, like any other parent would say. And I told her how I googled it. I googled all my symptoms of night sweats, lump, um, this nasty cough, my sister said it sounded like. What did it sound like? I guess whooping cough [her sister can be heard saying smoker's cough in the background]. It sounded like whooping cough. And then, and-and then, um, when I googled that—thank you Google. It said Hodgkin's lymphoma, and the minute I saw Hodgkin's lymphoma, I was like that's what I have.

Exhale.

Consistent with the quest and restitution narratives, the patient starts her narrative in the pre-liminal stage with symptoms leading to diagnosis. She even turns to Google to assess her symptoms. As I said in Chapter 4, Google did not exist when I had cancer. In fact, it came out the last year of my treatment. Had online information been more available, I likely would have searched my symptoms, but I am not so sure I would have claimed my own cancer diagnosis in the way she does. Unlike the restitution narrative, when she says, “I diagnosed myself—thank you very much,” she exerts authority over her diagnosis, claiming it as her discovery. She becomes an active agent with agency in her cancer story. A quest narrative places the storyteller as the active agent, or hero, in one’s own illness story and thus exposes control over the uncontrollability associated with narrative wreckage from illness and its chaos. As chaos begins to emerge, her story becomes an automythology quest narrative, wherein a patient’s actions seek and/or use alternative resources to manage the uncontrollability of illness. She reveals her active information seeking through using Google as a resource to manage her uncertainty of symptoms.

The patient’s embodied telling is dramatic. When the patient describes telling her mom that Google says her symptoms are consistent with Hodgkin’s lymphoma, the patient clears her throat and then makes an uppity voice to say, “and that’s cancer.” She then performs her mother, changing her voice to have a sharper tone “No it’s not! You don’t have cancer; that doesn’t run in my family.” In describing her mom’s response, her mother concludes cancer as an impossibility because of a family history. In this, her mother exerts authority over her daughter’s self-diagnosis. However, the patient remains active in telling, in which she discounts her mother’s nonbelief, “and, she was talking all of that, no, you don’t have cancer stuff, like any other parent would say.” Cancer is atypical for teenagers, and parents may make sense of their

children's cancer symptoms through socially constructed expectations of what is and what is not normal for adolescents. I remember complaining to my mom for a month or so. She brushed it off, telling me I was fine. She concluded that I was doing "too much," and I needed "to cutback" extra-curricular activities. This led to a late diagnosis and when pediatric oncologists diagnosed me, they said I would not have survived the week.

Inhale. Hold.

Mm-hmm, I claim it. And I told my mom, and she was like, we was in New York City, my sister was getting something . . . So, this is October thirtieth, and we went to Mercy Hospital. And, they did an x-ray, um, they did an x-ray. And, I think that's all they did. And, then they was like, they put me in this other room and then not even a room; it was just a curtain. Oh, I don't have to get in to detail, sorry, off topic. They put me in this other room, and then, there they handed my mom this paper that said oncology. And I didn't know what that meant. So, I just took out my phone. And, then I was like Google oncology. And then it said cancer. And then I was like, I was right; I was right! But I wasn't like all that happy. I was like, damn, I was right.

Hold.

The chaos of cancer along with its uncertainty and uncontrollability emerge in the above passage as the patient realizes the certainty of her earlier prediction: she has cancer. The chaos narrative is a disruption to one's biographical story. Storytellers often describe chaos through a series of contingency statements such as, and then this happened, and then that happened, and then this happened, and so on and so forth. The chaos narrative places the patient as a victim of disease or illness. In the above passage, her "and then" statements increase, exposing the uncertainty and the uncontrollability of her new role as a cancer patient and the initiating ritual performances she experiences in the process of diagnosis. The patient exerts agency when she, again, uses Google to manage the uncertainty related to unknown information, in this case, the word "oncology."

Because of her self-diagnosis, her threshold into liminality is blurry at best. For Frank (1995), diagnosis is the threshold. As I mentioned in Chapter 4, the physician's diagnosis of my cancer was a performative speech act, in which its perlocutionary effect was my narrative liminality. The patient in the above passage first diagnosed herself, making her medical diagnosis a confirmation of her earlier conclusion. When the patient tells the last part of the passage, she learns what the word "oncology" means. Until this point, her embodiment of telling is confident. For example, she says the following line like a kid who is bragging, "I was right; I was right!" Then her pitch lowers to say, "I was like, damn [long pause]; I was right." This moment is the first time in her story when she negatively reflects on the process of her cancer diagnosis, a result from actively seeking information to reduce and/or manage the unknown word oncology. For Frank, her reflexivity in the experience of diagnosis and the events that follow are necessary for the transformation from victim to victor that occurs at the end of a quest narrative.

Liminal Stage—From quest to chaos to restitution, shifting from active to passive roles

And, then [my family] came to the hospital and so yeah it was nighttime because I went to the hospital around 4pm, and then I left around 12, I guess. And, so they went to the hospital, and then we drove home. And, then tomorrow, the next day, we had an address and we had to go to that hospital because that's what they treat. And the next day was Halloween, I wanted to be a vampire, thank you very much, but instead I was a cancer patient. Okay. I understand that. Um me and my sister was so happy like the week before that. We went to Walmart, and, you know how they have those vampire things and all that for like five dollars. And, so we was going in, we spent all that money for no reason. And, I wanted to be a vampire but I was a cancer patient instead. And, so Halloween is my anniversary cuz that's the day they diagnosed me with Hodgkin's lymphoma.

Inhale. Exhale.

The patient's chaos grows along with the uncertainty of her experiences associated with the process of her diagnosis, evident in her continued use of "and then" statements throughout the last two passages. "On the control dimension, the body telling chaos stories defines itself as being swept along, without control" (Frank, 1995, p. 102). The victimization of disease or illness

partly situates in a patient's passive movement through an uncontrollable illness narrative; things happen to the storyteller. The switch from her first-person narration of her active role to her first-person narration of her passive role, moves the storyteller from a position as an agent with agency to a position as an agent without agency. This passive role is consistent with the chaos involved in the liminal stage of the quest narrative and the restitution narrative.

In the above passage, the patient not only switches from an active to passive role in her narrative but also maintains a first-person narration in which the temporality of her language shifts to an implicit conditional past tense statement for her present being: "I wanted to be a vampire, but I was a cancer patient instead." Thus, if she could have continued along the narrative path she had before cancer, or her idem identity, then she would have been a vampire. In this moment, the patient describes the disruption cancer has on her narrative identity. "And the next day was Halloween . . . me and my sister was so happy . . . We went to Walmart, and, you know how they have those vampire things . . . And, I wanted to be a vampire, but I was a cancer patient instead." As she concludes the above passage, the patient describes and embodies her narrative identity and the apperception involved in her liminality. In the words of Turner, she is 'betwixt and between' two positions—her teenage narrative self and her new role as a teenage pediatric cancer patient entering a cancer narrative. As she embarks on her cancer journey in which her performance of performative rituals will instate her cancer identity.

It's kind of weird, so, the next day I was at north shore-LIJ Cohan's Medical Center. It's a long name, I'm sorry. Um, and there I met Ingrid, which is my social worker . . . And, I met Dr. Atlas. And, I met, I forgot the other doctor's name. There's so many doctors. Um, but right now I'm with my pedia-pediatrician Sandra. Um Dr. Redner, which is the main doctor, she's the boss. Um, who else am I missing? Dr. Levy, and ok, who am I missing? Those guys, my doctors, um, they diagnosed me with Hodgkin's lymphoma 2b, which was, I have cancer and my lymph vessels: cervical nodes and thymus nodes. Oh, I remembered! And I went through, um, what was it called? A bone marrow biopsy, to see if the cancer was in my bones, which it wasn't--thank God. And, I went through a biopsy on my neck, and that's how they diagnosed me, of course. Um, what else did I go, and for

all of that, well, for the um biopsy on my neck, I wasn't, I wasn't under anesthesia. So, I was up. I mean, I was under anesthesia as in I didn't feel it, but I wasn't asleep. I was just there watching the screen . . . that had like the, um, like ultrasound. It was like having the gel on it and stuff. And, I was like ew, that's the inside of me, and whatever.

Inhale. Exhale.

The patient's liminality continues as she expresses more contingent statements when recalling her experiences of the rituals associated with her process of diagnosis. These ritual performances are uncertain and uncontrollable as they rapidly initiate her into a cancer patient identity. As she describes the numerous physicians, her actions are passive, and her uncertainty becomes apparent when she is unable to recall all the physicians: "I forgot the other doctor's name. There's so many doctors," and "Um, who else am I missing? Dr. Levy, and, ok, who am I missing?" I think of the numerous pediatric oncologists I had; I can remember them all by name, but rarely does my story include them all. She no longer tries to recall all the names of her physicians and moves toward her medical diagnosis of cancer. "Those guys, my doctors, um, they diagnosed me with Hodgkin's lymphoma 2b, which was, I have cancer and my lymph vessels: cervical nodes and thymus nodes." Though she becomes excited when she can remember the exact name of her diagnosis, the chaos of her story breaks her chronological telling. After she states her cancer diagnosis, she goes back to describing the medical rituals leading up to her diagnosis such as her "bone marrow biopsy," the "biopsy of [her] neck," and her "ultrasound." Her sister, off camera, excitedly says, "that's your cancer story!"

No, it's not! I went through so many MRIs. I hate MRIs, they're the worst thing that you can go through. Seriously, they're so loud; they scare me. Once I was going through a MRI like at nine in the night and then I was just having a panic attack. I was like, oh my gosh get me out of here. I was squeezing the little ball thing, to get me out of there.

Inhale. Hold.



The patient denies her sister's statement, claiming the experiences already told constitute the patient's cancer story. The patient immediately describes more chaotic experiences such as the uncontrollability of being in an MRI machine, which I wholeheartedly agree. When getting an MRI, I always felt claustrophobic. The experience is very unpleasant, though I would not describe it as "the worst thing that you can go through." The spinal taps, bone marrow aspirates, radiation, vomiting blood for hours, losing my hair and a host of other things were among some of the most unpleasant experiences I had. Though, I am not sure which one of those experiences would be the worst thing to go through.

Hold.

Um, my first roommate was this girl named Amanda. And, every time I go to the hospital I want to be her roommate. I was only her roommate twice. And, her family is so nice, and her grandmother. Um, and that hospital it's like you can't get a nurse that you're not gonna like. It's like every nurse that you get, you're gonna like. You know? You know how many times I went into the hospital in the ER because I had a fever from having chemo had four sessions of chemo. And, I had chemo Wednesday, Thursday, and Fridays. My, I think, Friday or Wednesday chemo was the worst. And, so I was in the hospital for like, how long? Three weeks, yeah . . . It was, it's so cool, um, being in the hospital around Christmas time you get so many presents. It's the best.

Inhale. Hold.

I think of Paula; she was my first roommate when my pediatric oncologists diagnosed me. I spent the following thirty days in the hospital completing my induction phase of chemo. Well, they let me go home for Christmas Eve and Christmas. Paula was a baby around six months old. Paula and I both had leukemia, but her odds of living through cancer were worse than mine. Her parents were young and friendly. They were Mexican-American or perhaps some other Latin country. I vaguely remember her parents speaking Spanish, but my Spanish is terrible. I remember my mom telling me that her parents could not afford treatment or that they did not have insurance, or maybe it was both. Paula is important to my story, she is the impetus

for moments of quest in my cancer story. After my diagnosis, I paid little attention to anyone but myself. My feelings of anger and helplessness consumed me as medical treatment governed my body. I did not understand what I did to deserve a late cancer diagnosis. I kept thinking of what the attending pediatric oncologist said, that I would likely not survive the week. I was so mad at everyone and everything. Then there was Paula. On my fourth or fifth night in the hospital I awoke to Paula screaming. The phlebotomist drew blood for labs. They would draw blood from the entire floor every four hours. Or was it six hours? Anyhow, Paula expressed her experience in cries and screams. Up until this point, her screams and cries had upset me, but this time I thought about her life compared to mine. I had sixteen years of life; Paula only had six months. Paula could not understand what was happening to her body nor could she speak to express her discomfort. And there I was complaining about my diagnosis being unfair. She was born with leukemia. How was life fair to Paula?

I tilt my head down and to the right,

Bringing a cigarette to my lips.

I raise the lighter to reach the cigarette's tip,

Rolling my thumb to spark its flint.

Deep inhale.

Slow exhale.

Repeat.

Right now, I don't have any cancer in my chest, but I still have cancer in my neck, so no more chemo treatments, they're not sure what they want to do radiation. And they have this surgery that they want to do, but they-they said it's dangerous, but I would rather have the surgery than radiation, because I wouldn't want to get a second cancer . . . And that's my cancer story! I'll keep you guys updated . . . I might have school this year . . . Finally, I get to go to my new school, people already know me, so I got it like that . . . Um, so that's my cancer story, thank you for watching. Um pray for me.

Like the patient from Video 1, she does not end her story in the post-liminal stage of the quest or the restitution narrative, but whilst still liminal. Albeit, she is closely approaching the post-liminal stage when indicating the absence of cancer in her chest and her upcoming completion of treatment. However, she still has cancer in her “neck.” To be near the end of chemo therapy and still have cancer in her body is not a good sign. In fact, because of this, she has an ambiguous course of future medical action: to have surgery or to have radiation. Through this ambiguity, the patient perpetuates uncertainty and uncontrollability associated with the chaos of her illness and the failure of restitution. Her story leaves her in liminality, and her choice for future actions will bring about another course of actions.

Her worry of radiation causing a second cancer is also in my story. I had complications from the methotrexate I received, which was the most common chemical in my treatment. I received methotrexate in various ways: intravenous, intramuscular, and intrathecal. When my pediatric oncologists administered intrathecal injections of the drug, or in injecting it into my spine, they intended it to prevent cancer from developing in my spine and central nervous system (CNS). However, I had complications with the intrathecal injections, starting with migraines. The complications increased with each injection, and the third time, the drug caused a bad chemical reaction in my brain. I experienced an episode of intermittent spastic movements followed by a vegetative state. I could not function for nearly a week. When I woke, I could not remember what had happened and I was having trouble with the two hemispheres of my brain communicating. For example, I could tell what time it was, I just could not say the time. My pediatric oncologists contacted St Jude’s hospital, who contacted another hospital in Europe who was administering a non-methotrexate therapy for Leukemia ALL-B cell. Soon, my physicians administered a new chemo therapy protocol, excluding intrathecal and intravenous methotrexate.

Because of the danger of cancer developing in the spine, my parents had to decide to do radiation or not. The radiation of my spine and CNS was to be a substitute for the intrathecal methotrexate. Physicians explained to my parents, not to me, that the radiation could cause brain or spinal cancer. I did radiation for six weeks along with my chemo, and it was awful.

Inhale. Exhale.

### **Video 3: Wilms Tumor—falling from remission: restitution, chaos, and quest**

My black laptop sits on my black glass coffee table. I look at the screen. I see a video icon; it shows a young white adolescent girl sitting in her hospital bed. She has a shaved head but the heavy makeup on her face almost makes her look like a doll. I scroll down to select her video titled, “My Cancer Story.” I click on her video and the image expands; I can clearly see her face. She wears a sincere smile. I enjoy watching her dimples peak through her cheeks. I try to remember if I smiled like that when I had cancer. She looks healthy and happy. The only thing that marks her as different is her shaved head and that she is in a hospital room.

#### Pre-liminal: passively entering a restitution narrative

Hi . . . I guess, I'll tell you kind of my backstory but, like, cancer backstory. So, I was first diagnosed when I was six years old. Um, what happened was I was having pain in my stomach and, so, for a while we might have thought I might be constipated or something small like that. So, I stayed home, and my mom just tried to get it under control, but we couldn't. And then one day I woke up and there was a big lump on my side—on my side—of my stomach. So, we—my mom decided to take me to the ER—my mom and dad decided to take me to the ER. And we came to Covenant in Lubbock Texas, and once we got here they did CAT scans and stuff to try to figure out what it—what it was and as soon as they saw the tumor they decided to do surgery—go in and do surgery. And so, when they got in they realized that it was a tumor, and it was in my kidney. So, they took my whole kidney and the tumor, my left kidney to be exact, and then I did —oh and that tumor was the size of three softballs. So, then I did about a year of chemo and some radiation.

The patient begins her story with a huge smile on her face, she introduces herself and waves to the camera. Her facial expressions are animated; she often opens her eyes wide and

raises her eyebrows when looking directly at the camera. She indicates this video is the first of a vlog series about “living with cancer.” When the patient describes her “first” diagnosis at six-years-old, her adolescent body signals to me she has endured cancer for several years. Consistent with restitution’s pre-liminal stage, the patient begins through describing symptoms starting with pain in her stomach. Like the two other adolescent patient stories, this patient introduces her parents in the story’s exposition. This patient shares a similar story with the Hodgkin’s lymphoma patient and myself, in which her parents make sense of her symptoms in ways that delayed her diagnosis; her mother treats her for constipation; her pain was not enough for her parents to take her to a physician; it was not until she had a large noticeable anomaly of her body, a “big lump,” until her parents took her to the doctor. I wrote earlier about how my symptoms were mild at first and even when they grew worse, no one, not me or my mother, thought it could be cancer. Of course, Google did not exist when I received my diagnosis.

The patient continues a chronological telling but switches from an active to a passive role in her cancer story, evident when she shifts her syntax from a first-person to a third-person narration. “So, we—my mom decided to take me to the ER—my mom and dad decided to take me to the ER.” Here, she gives agency to her parents when she switches narration and her parents control her actions. Throughout the patient’s story she switches between first-person and third-person, but her growing use of third person plural begins when she describes medical authorities controlling her action in the story: “as soon as they [medical authorities] saw the tumor, they decided to do surgery.” From this point forward, medical authorities increasingly play the role of active agents who exert agency in the story. Like the patient in the first video, she also refers to medical authorities as an anonymous “they,” and they have authority over her body. The patient’s excitement in telling her story seemingly lessens until it disappears when she describes

the removal of her kidney along with her tumor. The patient has not yet mentioned her diagnosis of cancer in this first passage. In various ways the viewer has likely learned or inferred she has cancer, yet since she began her story, she has not mentioned a cancer diagnosis, but ends by saying she “did about a year of chemo and some radiation.” afterward she looks off camera and takes a long pause.

Inhale. Hold.

Liminality: a chaotic feedback loop—post-liminal, pre-liminal, liminal—repeat

I had been clean for a little while, not very long, and I came for my scheduled, um, checkup just . . . to see if there was any new tumors growing and so they found another tumor about the size of a golf ball, I think something like that, in my right one. So, they went in and they got that out and I did another year of chemo and some radiation and then, I, was clean for a little while and then I started having pain in my stomach again . . . So, they did more CAT scans . . . they thought I had appendicitis, so they went in to go get my appendix out and they found another tumor but thankfully it was dead so that time they just took the tumor out and I didn't have to do any chemo or radiation. So then after that, about a month later, I had a bowel obstruction just from the surgery so they just went and fixed that . . . And that December I was clean for three years and that January I had scans and they told me that I was cured. And then that March I had more pain in my stomach and my stomach got so swollen that it looked like I was pregnant so we decided again to come back to the ER and they did more CAT scans and we—they found a soccer ball-sized tumor in my abdomen. So, they went in, took it out, they found out that it was the same cancer as I've had the whole time, Wilms tumor . . . I don't think I told you that at the beginning . . . so they took the tumor out and I finished. I had to have eight days of radiation . . . then I came back and now I am in the process of chemo and Wilms tumor doesn't usually come back . . . they don't really know what to do.

Hold. Hold. Hold.

In this passage, the restitution narrative moves to the background as the chaos narrative moves to the foreground. Elements of the restitution narrative persist through the patient's chronological arrangement and passive role in which medical authorities direct the movement of the patient's body through her story. Like videos 1 and 2, this patient's chaos is evident in her numerous contingent statements (e.g. and this happened. . . and then that happened . . . and so on and so forth). These statements describe the patient “being swept along” (Frank, 1995, p. 102) by

medical authorities who direct the patient's actions in the story. Unlike Video 1 and Video 2, this patient's story exposes repeated failures of restitution's post-liminal stage and thus a failure of the biomedical approach to restore her health. In the above passage, the patient describes a chaotic feedback loop between receiving a cancer diagnosis and being cancer free, a cycle that repeats the pre-liminal, liminal, and post-liminal stages. This cycle of chaos is akin to, if not worse than, Zeus's punishment of Prometheus. For his crime of theft, Prometheus remains eternally chained to a rock and each day an eagle eats his liver and each night Prometheus grows another liver—perpetually stuck in the endless cycle of suffering. Though there is a passive uncontrollability for Prometheus, he has certainty of the eagle's return. In the case of this patient, the only certainty is uncertainty.

The patient's chaos narrative exposes the vulnerability of human life and the failure of the institution of medicine to enact her restitution. The chaotic feedback loop is more than her back-and-forth movement between having cancer and not having cancer, it is also her back-and-forth movement between healthy and unhealthy, between normal and non-normal, between futurity and no futurity, between life and death. In addition to her movement between binaries, the patient uses the word "clean" to mean free of cancer. The word—clean—then functions as a metonym, standing in for the word healthy. If clean stands in for healthy, then to be unhealthy is to be unclean, and cancer becomes a dirty word. I draw on Warren's (2003) work in *Performing Purity*<sup>48</sup> to expose privilege in the underlying binary: healthy/unhealthy. The patient's use of

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<sup>48</sup> In *Performing Purity* (2003), Warren explores the white/black racial binary, suggesting publics view performances of whiteness as pure and performances of blackness as impure, in which there is a conflation of the racialized body with racialized performances. I parallel health to Warren's concepts through three dimensions: (1) health is a social construct; (2) performances of health (re)constitute its power and privilege as a social norm; and, (3) discursive representations of health through portrayals of the body and bodily performances influence the public's attribution of the body as a signifier of health, signifying healthy/unhealthy performatives.

“clean” as a metonym for healthy can expose the purity presumed upon bodies and bodily performances signifying health. In this frame, health is a sociocultural construct, in which healthy bodies and their identities maintain a power and privilege over unhealthy bodies and their identities. Not only does the healthy/unhealthy binary underlie illness narratives, the privileging of healthy-bodied aesthetic makes it a sociocultural compulsory. To be healthy is an obligation, and performances should seek toward healthy rather than unhealthy, reinforcing its biomedical telos.

In her dialectical movement from healthy to unhealthy, the patient becomes a victim to the uncontrollable chaos of cancer in which becoming victor (the telos of restitution and quest narratives) can appear impossible. In a true chaos narrative, “no one is in control” (Frank, 1995, p. 100). This uncontrollable chaos creates a “narrative wreckage” (p. 110). One that is not simply a collision of narratives, but a disruption to, and an undoing of, one’s narrative identity. The liminality inherent in chaos places patients in an interstice, a position of antistructure, or as Frank calls it, the “anti-narrative” (p. 98). Chaos stories can not only expose narrative structures for what they are, but also can provide new possibilities for patients—new ways of being in the world. In a patient’s reflexivity of the narrative wreckage caused by chaos, a transformation of the patient can take place.

Today, I'm in the hospital just for my scheduled chemo and I guess knowing that—knowing that my chemo is all experimental is scary, but any chemo’s scary . . . if you are going through it . . . you just have to remember that God has a plan for you. You have to keep all your faith in God because what else are you gonna do? Because, we're not strong enough to do it on our own. We have to have God's help. So, you just have to have faith in God, it's one, that's the number one. And, also, you never stop fighting, never. Once you give up your fight you've given up and you've let the cancer win. So, you can never give up your fight. You have to keep fighting no matter how many times it comes back, no matter how much chemo we have to go through, no matter how scary it is, no matter what the odds are. You just have to keep fighting because that's the only way you're going to win. And those are the top two things . . . number one is to have faith in God



because he has a plan for you even though you may not know it or you may don't like, it it's his plan so it's the perfect plan. Number two is to always keep fighting, always.

Exhale.

The uncontrollability and uncertainty associated with the chaotic cycle of despair culminates in the experimental chemo regimen with which the patient is about to undergo. Because neither medical authorities nor the patient controls the uncertainty in a chaos narrative, the goal of restoring the patient's health becomes more a matter of hope. In this last passage, the patient offers two pieces of advice for viewers who are undergoing chemo therapy. In the first, she suggests putting faith in God. God becomes the authorizing agent with agency who controls the uncertain outcome of her living or dying: "you just have to remember that God has a plan for you." God's plan restores a controllability to her narrative and accounts for the uncertainty through God's altruistic predetermined outcome for her life. As mentioned in Chapter 2, this is known as a secondary-coping mechanism of illusory control (Last & Grootenhuis, 2012), in which the patient relinquishes control to fate. For this patient, faith is a requisite for God's help and God's help is a requisite to endure cancer: "we're not strong enough to do it on our own. We have to have God's help." 'God's plan' is something I heard often when I had cancer. I immediately think of my roommate Paula. What was God's plan for her? A child born with leukemia only to die from leukemia before she could talk or walk. Paula's parents could not afford her treatment but went in debt to have her treated. Giving control to God is a way in which one can cope with the uncontrollability of chaos. Unlike the patient in the above passage, I was angry at God's plan because the plan included me having cancer at sixteen-years-old. What about my plans?

Like this patient, I underwent "scary" uncertain experimental chemo and radiation treatment, which moved my narrative from restitution to quest. I found pride in the fact that my

body provided evidence-based research that might help future patients with leukemia who had similar complications with methotrexate. In a way, I felt like, if I died, then my life would live on in that research. I was also rather happy to stop the frequent Lombard punctures (spinal taps) required for intrathecal injections. Those were not fun. Consistent with the quest narrative, the uncertainty and uncontrollability of my situation led me to exert agency through employing a proactive meaning-focused coping strategy (see Chapter 2). I began my own experiments. I remember thinking: I do not consciously control much of my body such as breathing, heartrate, and blood—unconscious parts of my brain, like my medulla, control those parts of my body. However, I can consciously affect my breathing and my heartrate, I can modify them—partly control them. I wondered if this was possible with my blood. So, each night before I went to sleep, I would visualize my good white blood cells attacking my cancerous white blood cells. I will never know if my visualizations worked, but my actions gave me a sense of control over cancer. Like the teller of an automythology quest narrative, I actively sought to control the uncontrollability of cancer through seeking alternative resources.

Though God takes an active role in this patient's story, the patient ends her story by contradicting that role through her use of language consistent with the quest narrative. As mentioned in Chapter 2, the quest narrative is about gaining control over the uncontrollability and uncertainty involved with illness. A patient in a quest narrative is an active agent with agency, who becomes the hero of one's own story. After the patient gives her first piece of advice about having faith in God, she then suggests that other cancer patients should "never stop fighting," exposing the agonistic relationship between her role and cancer as adversarial. Sontag (1978) indicated "every physician and every patient is familiar with, if perhaps inured to, [the language of warfare's] military terminology." The patient's application of this dramatic language

is most consistent with quest's automythology narrative, as one actively fights or battles cancer. Her use of this language is contradictory within God's active role in her story. The patient claims we need to have faith in God "because, we're not strong enough to do it on our own." Yet she also claims, "once you give up your fight, you've given up and you've let the cancer win." If God has a predetermined plan, then why does fighting matter at all? And, if you lose, then does that mean you did not fight hard enough? Or, was it God's plan for you to die?

Inhale. Hold.

#### **Video 4: Surviving Ovarian Cancer—A Long and Chaotic Journey to Restitution**

I lay on my gray couch; my laptop sits on my lap. My left arm dangles on the side of my couch and my left hand swivels an empty glass holding a single ice cube. I like the sound it makes; it soothes me. My right-hand scrolls through videos of cancer stories and I come across another video titled, "My Cancer Story." The video has 22,182 views and has been public for just over a year. The video icon shows, what looks like, a teenage white female. She has long blonde hair and full eyebrows. She does not look like she has had chemo or radiation—at least not anytime recent. I click on the video and it enlarges. She has piercing hazel eyes, which pick up the periwinkle blue and white plaid shirt she wears. It appears as if she is in her bedroom. The walls are white, and to the right, the wall has large black leaf cutouts spread all over. Daylight fills the room from a window out of sight, its reflection evident in a mirror against the back wall. In the background, her closet door is open—only three outfits hang. The clothes are solid: red, black, and white. The red and white outfits properly hang on the rack, sandwiching the black dress in the middle. However, the black dress does not hang, it drapes over the other two clothing items, facing front to the camera. It is as if she has plans to wear the dress today. She is very boisterous as she begins her story with a series of disclaimers.

### Pre-pre-liminal: Disclaiming her testimony

I'm going to share my testimony with you all, so I want to start off by saying, yes, I am a Christian. I was born into a Christian family and, um, now I am a Christian by choice. With the things that I've been through God has shown me that through His love and through His grace, that anything can be defeated. I'm 19 years old right now, just to give you just to give you kind of an idea of where like the timeline of all of all this. Disclaimer, I'm going to talk about very personal things, so it might make you uncomfortable. I'm sorry.

Hold.

To give a series of disclaimers is to worry about your audience. As a writer, I connect with her disclaimer. I have done disclaimers out of concern for my reader, or perhaps a concern for how my readers perceive me—I am not sure which, maybe both. When writing a disclaimer, I often include elements about my writing, or how I felt about my writing. Her disclaimer has elements that remind me of the last passage by the patient in Video 3—Wilms tumor. This patient not only foregrounds her religion, but she also places God in a role that helped her *defeat* cancer. Though this is different from how the patient in Video 3 describes “God’s plan,” there is a similarity in that God is a requisite in the battle against cancer. Additionally, this patient frames her cancer story as her “testimony.” As mentioned in Chapter 2, Frank (1995) suggests survivor stories are testimonials. The patient is a witness to cancer through which her story and her body are both a testimony of her fragmented truth about cancer and the narrative wreckage it has created in her life.

### Pre-liminal stage—Chaos and liminality before the liminal stage.

I was sixteen-years-old. I, um, I was having my period every two weeks and I was just kind of like, ugh, that's not normal. I don't want that, I mean, not that I don't need it—it wasn't even that I didn't want it, it just was something that I didn't think was normal. I went to my doctor and I was put on birth control; it regulated my period for . . . a couple months and then after I think about eight months . . . it stopped my period all in all. And I, thought that wasn't normal so . . . I stopped taking it. And then the following winter I *went—I go* back to my doctor and I say, “okay, I stopped taking the birth control. I'm not getting good, um, just like reactions from it.” So, I was gaining weight I was—I was just

moody all the time so, I mean, it's . . . hormonal medication, it's what it's going to do to you. And, so, I stopped taking it and then I went to my doctor, I told my doctor, “Hey, um, I don't—like, what can I do without having to take birth control?” and he said—or she said, “I'm going to put you on a ten-day a hormone medication.” So, she did, and ten days go by and nothing happens; my period is still gone. This was in January—and then—or no, this was in December and then I came back in January and I did . . . hormone medication, again; it did nothing to me. And then she told me just to kind of wait it out and see what happened. So, this was . . . the beginning of 2014, and I wasn't—I wasn't having my period, and everything was fine. It just wasn't normal.

This patient chronologically begins her story by describing symptoms of her changing body. Consistent with Frank's (1995) restitution narrative and its pre-liminal stage, her symptoms lead her to see her physician. Though the storyteller's symptoms regarding her menses are atypical—or as she said, “not normal,”—her physician mistreats her body by treating her with hormones for well over a year. In this experience, the storyteller does not describe having any blood tests or diagnostic work during this year, just that her doctor continued to prescribe hormone medication. After a year of ineffective hormone medication, she says her physician tells her “to kind of wait it out and see what happened.” The uncertainty and the uncontrollability of what is happening to her body increases throughout the passage.

Chaos surfaces in the pre-liminal stage of her restitution narrative, which is suspiciously liminal. Degrees of chaos and its disordering of her “normal” body make her pre-liminal stage blur her threshold into liminality. She is ‘betwixt and between’ being a normal sixteen to seventeen-year-old female with menses and a non-normal sixteen to seventeen-year-old female without menses. To be bound to the concept of normal is to be a normal teenager. I was sixteen-years-old when I received my cancer diagnosis and what was normal and not normal was a great concern for me. After my official diagnosis, I was in the hospital and one of my pediatric oncologists stayed up with me one night. She did her best to complicate how I saw the word normal. I remember her saying, “You are not a statistic, Patrick; you are a human being.” She

seemed to care deeply for her patients, and she also had a PhD in psychology and worried I saw myself as abnormal. Cancer stories are not only a person's movement into an illness narrative, but also descriptions of being and becoming different through changes in the body and ritual acts initiating and instituting a cancer identity that produces and reproduces illness narratives.

I just kind of didn't think anything of it and then, um, I realized in August . . . changes were happening to—happening to my body; things were being different. Um, something wasn't right with me and I realized in that moment that I was dropping weight, I wasn't having an appetite, and it—it just it started to get more severe and severe and severe. I was having these pains on my right side and it almost felt like someone was stabbing me, but I wasn't—I wasn't cramping because I didn't have a period. And, so, I went to my doctor and I told him everything that was going on. He, like, felt my stomach and—and then . . . he's like, “Oh, well we—I don't know what it is so I'm gonna send you to—an ultrasound.” And I looked at him and I said, “as long as it's not cancer, I'm fine.” Little did I know I was actually jinxing myself at that moment, um, and this was a Monday.

Exhale. Inhale. Hold.

The patient's chaos continues as her symptoms worsen, directing her toward restitution. Bodily changes indicate to her “things were being different” in a way that “something wasn't right.” As she indicates losing “weight” and a loss of “appetite.” I immediately think of my cancer story and the symptoms I had leading up to my diagnosis. My loss of appetite was subtle, at first, which made my weight loss less noticeable. At my high school, we had a lot of fast food options, and almost daily I would get The Taco Bell Special, which was two burritos and a soda for two dollars. I remember I had started to feel full, rather quickly, so I would eat less and less each day. A week before my diagnosis, I would only take a couple bites of one burrito, and then give the rest away to my friends. By the time oncologists diagnosed me, I had lost twenty pounds. Like the development of her cancer to cause noticeable “stabbing” pains on her right side, my leukemia developed to cause paralyzing joint pain, making it impossible for me to move. In accord with the restitution narrative, the impact cancer had on each of our bodies was the impetus to visit a physician. She, however, has a new physician in this second passage, now a

male. She does not indicate when or why she switched physicians. Perhaps she sees whichever physician is available at a clinic. Or, perhaps she did not like her last physician's 'let's wait and see' approach. This physician necessarily orders an ultrasound.

I go to my ultrasound and, um, I went in thinking it was an infection, to be honest, but it ended up being . . . a much bigger problem than I anticipated it to be. I sat there on the table and she was, I mean I looked like I was . . . three months, four months pregnant and, um, the nurse, the ultrasound tech took pictures of my abdominal area and . . . my mom told me that she seemed really worried. I—I guess, I just wasn't paying attention to it because I just thought I was going to be okay. I had two—I had two sets of pictures taken, one with my bladder full and one with my bladder empty. And I just sat there and I remember . . . pulling my shirt down and the nurse left and the radiologist comes in and he looks at me and he says, "Is nurse so-and-so here?" But, I didn't remember her name. And I said, "Oh, I don't know." And he sort of, like, closed the door super-fast. He comes back in with the—following the nurse and he's like, "You might want to sit down." And, I looked at him and I said, "No, I'm fine." I'm super stubborn, so I'm like, "No, no, I can't sit down; I'm fine." And he's like, "No, no seriously you want—you might want to sit down." And I said, "No, I don't want to sit down." Like, don't tell me what to do.

Hold. Hold.

As the storyteller further details her passive movement through the restitution narrative, in the story she approaches diagnosis and its threshold into the liminal stage. At this point, her body is different; she looked as if she was "three months, four months pregnant." I wonder if she had to buy new clothes to accommodate her pregnant-like belly. Medical authorities evaluate her body through an ultrasound and showing her pictures of her abdomen. When describing this experience, she primarily maintains first-person narration using a past tense or past progressive tense, but when she moves into a dramatic mode of telling—an embodied telling of the conversations in her story—she uses first-person historical present tense. Like the patient in Video 2—Hodgkin's lymphoma, the storyteller seems to relive her past experience through her telling. Her speech rate drastically increases in describing the conversation between her and her radiologist, "'You might want to sit down.' And, I looked at him and I said, 'No, I'm fine.' I'm super stubborn." In resisting the physician's suggestion, she exerts what little control she has

over her body. She continues to do so when the radiologist suggests again, “‘No, no seriously you want—you might want to sit down.’ And I said, ‘No, I don't want to sit down.’ Like, don’t tell me what to do.” She stops the video. In watching her, I flashback to my cancer story. As I described in Chapter 4, when my mom asked me to sit down, at first, I stood. At this moment in our stories, our bodies stand at the door to the liminal stage.

(Pre) Liminal stage: From a passive diagnosis to actively fighting alongside God.

And, so he said—he said, “All right, well, um, we found a mass on your right ovary.” And, I didn't know what that meant. And, I looked at him and I said, “What does that mean?” He said, “We think it might be cancerous tumor.” And, at that moment—I sat down and I looked at him and I said, “Are you serious right now?” And, I started laughing because . . . whenever anything bad happens, I start giggling. And, he said “Unfortunately”— and at this, at this point I'm *not crying*, but I look to my mom and she—she was crying. And at that point I knew it was serious and I knew it was scary and that I should be scared, because I didn't know what was gonna happen. I didn't know what was coming. And I remember going home that day and I was—I was really scared and I looked at my mom and I said, “Mom, I'm supposed to be applying to colleges and supposed to be looking for love and trying to make a life for myself and at this point right now in my life I don't know if that's a possibility. I don't know if I'm going to be able to build that life because I don't know if I'm going to be able to live it.” And honestly it was really hard for me to accept what . . . he had said. And, so I went into my room . . . and I sat down and I went to sleep because that was the easiest way for me to escape that reality, is to take a nap.

I tilt my head down and to the right,

Bringing a cigarette to my lips.

I raise the lighter to reach the cigarette's tip,

Rolling my thumb to spark its flint.

Deep inhale. Slow exhale. Repeat.

She begins this passage with her pre-diagnosis, which affords a type of certainty by explaining the uncertainty of what was going on with her body. The possibility of her mass being cancer adds another layer to the uncertainty of her experience. She did not expect to hear cancer and after saying, “at that moment” she takes a long pause and looks off camera dwelling in her



memory of that moment. I dwell along with her, stuck in my own memory of that moment when my mom said cancer. For both of us, this moment was scary and uncertain—halting. I am glad I sat down, when my mom asked me the second time. The potential label, having cancer, caused her to sit down. Though she was “not crying,” her mother was. I also did not cry, which surprised my pediatric oncologists, who said it is normal to cry. I think I may have been too angry to cry.

On the way home from the hospital, her uncertainty grows through her shifting futurity and the unraveling of her life before cancer: “I'm supposed to be applying to colleges and supposed to be looking for love and trying to make a life for myself and at this point right now in my life I don't know if that's a possibility.” Her uncertainty of her old life climaxes when saying, “I don't know if I'm going to be able to build that life because I don't know if I'm going to be able to live it.” She copes with the stress of this uncertainty through avoidance, taking a nap to escape “reality.”

I woke up and I did what every person should never do, I went on the Internet. Basically, I gave myself, like, six hours to live, so don't do that. I actually got down on my knees and I said, “Lord, this is a battle I'm not willing to fight without you.” And it's as if in that moment God took a bucket of strength and just poured it upon me and He said, “I'm here with you. I am fighting this battle alongside with you and I know that you will make it. And I said, “Yep, I got this.” And in that moment, I felt so empowered and I felt—I felt so good about what was about to happen and I was like “I can do this. I can fight this and I can win this” and honestly that's the mindset that I was I was supposed to have and for me to be depressed for those two days, it's not who I am and I've—and I've told people this before and if I was to go—if I was to meet that person from those two days, I wouldn't have recognized her because that's not who I was or who I am.

Inhale. Hold.

The storyteller maintains a chronological timeline as she passively moves through her illness story; however, in the above passage we see a transformation into her quest and its active role. Her information seeking, searching the Internet to manage her uncertainty, results in her reading information about cancer, which becomes the impetus for her to embark on her journey

as a warrior who will “battle” cancer. Like the patient who fell from remission in Video 3, this story also describes coping with cancer’s uncontrollability through secondary illusory control coping and military-like language. As mentioned in Chapter 2, secondary illusory control coping is a situational coping strategy through which an individual relinquishes control to fate. The patient may employ “praying, wishful thinking, or self-encouraging statements” such as having faith that God will see them through cancer. After reviewing online information about cancer, she gives herself “like, six hours to live,” immediately followed by her performative act of prayer: “Lord, this is a battle I’m not willing to fight without you.” From this point forward, she continues to use military language through which she will “win” this fight. She identifies as a warrior by making a distinction between how she first responded to having a tumor and how she is responding now. As mentioned in Chapter 4, I never saw myself as a warrior, nor did I see myself in a battle against cancer. I endured cancer. Yet, even in my cancer story, there are elements of the quest narrative and military language when I actively visualized my healthy white blood cells attacking my cancerous white blood cells.

And that night my mom comes into my room and—this is after my prayer and I felt, like, super encouraged and I felt so strong—my mom gets down on my bedside and she looks at me and she said, “I’m not ready to lose you.” And I said, “No, you’re not going to.” I wasn’t going to let myself not *win* this. I not only wanted to win it for me, I wanted to win it for the people around me, for the people who loved me, for the people who were fighting for me and praying for me. And, I had churches around the nation praying for me and for my healing and I felt encouraged to know that I had such a huge support system around me. And then . . . Friday night comes and I get admitted to Seattle Children’s and met with some surgeons and stuff and I couldn’t believe that this was my reality, like, that I was about to find out if I had cancer or not. So, I went home on Saturday because they didn’t have any openings for me—or didn’t have any surgery openings. And, so I came back on Monday and I had my right ovary removed with the tumor and my right fallopian tube, which connects your, um, uterus to your ovary and so I had that removed. Um, I’m sure many of you are asking if I can have kids or maybe you’re thinking that. I can, I still have my left one thank you, Jesus.

Exhale.

The military metaphor—cancer is a battle—transports her into the warrior narrative; she must actively fight to become a victor over cancer. This language helps her to cope with the uncertainty and uncontrollability she experiences from her changing body as well her quest to “win it for the people around” her. Fighting cancer for others becomes her call of duty through her feeling a responsibility to others. If she “wins,” the battle, then she will be a hero to them. The people around her, like her church fellowship, provide her with an encouraging “support system,” making her religion play an important role in her story. Like the patient’s story from Video 3, this story also merges the warrior narrative while relinquishing control to God through secondary illusory coping. Though quest moves to the foreground in her story, “both restitution and chaos remain background voices” (Frank, 1995, p. 115). She takes control through the warrior narrative, releases control to God, yet medical authorities still control her movement through the story and the uncertainty of whether she has “cancer or not.” After she passively describes the surgeon’s removal of her right ovary, her tumor, and her right fallopian tube, she presumes her audience thinks she cannot bear children. She ensures her audience she is still able to have children with her single ovary. I think of my own futurity and the uncertainty of whether or not I can have children. My pediatric oncologist told me that it is unlikely to have children due to effects of my treatment. She followed that by saying, “But don’t treat it like birth control.”

Inhale. Hold.

Post Liminal Stage: Defeating cancer before it diagnosis.

Um, my recovery was really, really quick; I think it's because I'm young. Um, my scar healed very nicely. It looks very good today. Um, it's just in my abdom—like from my belly button down to, like, my pelvic bone. Um, so, yeah, and then at this time I still didn't know if it was cancer or not and then two weeks later we go in for, um, a check-up to see how—if I’m healing and how I’m feeling and stuff. And, um, everything was super good and—and then that same day they told me, “You are diagnosed with stage 1-A ovarian cancer.” For some reason I wasn't afraid. I mean, thankfully, like, thank you, Jesus that I was—and I wasn't afraid. I wasn't scared and I was—I was accepting to those

words because I knew that I no longer had cancer, that I had defeated one of the scariest, um, diseases and illnesses known to mankind in our—in our day.

Exhale. Inhale. Hold.

As she describes her recovery from surgery being “really quick,” she goes on to describe her scar, making sure to note, “It looks very good today.” The scar permanently marks her body in ways that symbolize her experience, or battle, with cancer as well as her incorporation of her cancer story into her identity. The scar on my back hip marks my official diagnosis and my initiation into life with cancer. Numerous bone marrow aspirates caused the scar, but that first aspirate determined the type of leukemia—ALL pre-B cell. From that point forward my cancer story unfolds in the liminal stage until I complete cancer. However, this storyteller is still waiting to learn if she has cancer or not. She moves from the pre-liminal to the post-liminal stage, where her diagnosis of ovarian cancer occurs two weeks after the surgeon removed her cancer. Her cancer story depicts her journey to the door of cancer’s liminality, perhaps even opening the door to see the other side. However, if we consider this a tumor story instead of a cancer story, then the diagnosis of a tumor initiates her into a liminal stage, and the possibility of the tumor being cancerous adds another layer of uncertainty and uncontrollability to her experiences in liminality, in which she uses a quest narrative and the battle metaphor to cope.

And that is my testimony and I hope that this encourages people that whatever you're going through, that Jesus is going through it with you and that he's *fighting* the same *fight* and that he is willing to help you and—and I feel like sometimes not everyone *wins* the *battle* but the greatest *victory* is when we get to see God in Heaven—see your Father in Heaven I think that's—that is the ultimate *victory*. So, that is my story, um, yeah I think I'm just going to end it here. So, I hope you have a good day and just know that Jesus loves you and that I love you and I thank you so much for listening to my testimony.

At the end of her cancer story, she constitutes her battle as her testimony. She has reached the end of her quest and the experience has transformed her to be a victor over cancer. She thanks Jesus and God for helping fight alongside of her. Like the patient in Video 3, the type of

quest narrative that materializes is Frank's (1995) automythology. In the post-liminal stage, the storyteller "*returns* as one who is no longer ill but remains marked by illness" (p. 118).

Storytelling reshapes identity through looking back at the narrative wreckage caused by illness. For Frank, survivor stories are testimonials. To be a survivor of cancer is to witness cancer through personal experiences of seeing suffering and being a sufferer. In the being and becoming, the survivor's body is then its own testimony of illness, the body is complicit in cancer, and in the telling of a cancer story.

### **Expanding on Frank's illness narratives through Turner's Drama**

As mentioned in chapter two, Frank's (1995) quest and restitution narratives draw upon the work of Joseph Campbell (1949). Campbell articulated the hero's journey as narrating separation, initiation, and return. The underlying post-liminal stage is a return to health through medical treatment and cure. Campbell's hero narrative is an adaptation of French anthropologist, Arnold van Gennep's (1909) work on liminality. In looking at the cultural rites of passage involved with a new social status, van Gennep suggested three stages to having a new social position: separation, transition, and incorporation. For van Gennep, transition is the liminal stage, and incorporation returns an individual to society with a new social status and thus a new identity. Turner (1982) expanded on van Gennep's (1909) concepts of liminality, which can provide a deeper framework to analyze the liminal experience in illness narratives and their relationships to the body, its performance, and its identity. For Turner (1982), the oppositional movement from one "social status to another is often accompanied by a parallel passage in space, a geographical movement from one place to another" (p. 25). This movement dialectically marks the ritual journey through liminality. When a person transitions from healthy to unhealthy, there is typically a spatiotemporal separation from everyday life and into new medical settings (e.g.

hospitalization, clinics, diagnostics, et cetera). Turner's concept of liminality highlights the import of a threshold between two social statuses, wherein a person symbolically shapes identity through new ritual performances whilst liminal.

Ritual subjects undergo a 'leveling' process in which signs of their preliminal status are destroyed, in which signs of their liminal non-status applied . . . eating or not eating specific foods, disregard of personal appearance, the wearing of uniform clothing, sometimes irrespective of sex (p. 26).

Once diagnosed with cancer, there is no return to a previous identity. Medical authorities level "signs of [patients'] pre-liminal status" (p. 26) through a regulated daily diet, uniform clothing, and routines in which personal appearance is unimportant. From hospital gowns that expose bare bottoms to the bland hospital food diet with the not so memorable taste of green Jell-O left in your mouth, cancer patients clearly undergo a leveling process through hospitalization. New routines associated with hospitalization, clinics, diagnostics, labs, and more, force patients to perform new rituals and to learn a new language, in which every day routines greatly differ from one's past self.

Turner's (1982) theory of "social drama" (p. 9) suggests four sequential stages as to how liminality unfolds after a social disruption of everyday life, labeling them: breach, crisis, redress, reintegration and/or schism. I find this framework to be fruitful when exploring each video titled, 'My Cancer Story.' Not only can the sequential order of social drama serve as an underlying narrative structure for these teenage cancer stories, the liminality detailed in the redress stage can better describe the complexities involved in being and becoming liminal for these adolescent patients and myself. The coping strategies patients use to manage the uncertainty and uncontrollability involved with liminality's chaos situate in a patient's performances of redress. Additionally, Turner's fourth stage—(re)integration to everyday life or the schism from it—is contingent on performances of redress. Liminality, like the anti-narrative, is antistructure, the

spaces within and between constructions of normative sociocultural life. Turner's framework for social drama is applicable to these adolescent patient stories. Social drama highlights the import of the performing body and how ritual performances tie to social status. Using the four stages of social drama to reflect on these four cancer stories adds the body and bodily performances as contingent to the story and the reshaping of one's social identity: (1) symptoms of cancer *breach* the body's normative abilities; (2) the body becomes a *crisis* at the point of diagnosis; (3) medical treatment *redresses* the body's crisis through which patients experience liminality; and, (4) *reintegrating* the redressed body into the social order as a cancer patient and/or survivor of cancer, or *schism* the redressed body from everyday social life. Turner's four stages not only map on to Frank's (1995) three stages of illness narratives, but also add a fourth stage with two post-liminal outcomes—reintegration or schism—depending on redress. For Turner (1982), a new social identity is a matter of performing redress while liminal, not simply moving through the uncertain and uncontrollable chaos of liminality.

### **Presenting the Redressed Cancer Body**

I hated going into public when I had cancer. I mean, not just when I was living in the hospital or days when I felt terribly ill, but also days when I had plenty of energy. I did not want to see people and I did not want people to see me. I remember soon after finishing my induction stage of chemo, my mom took me to the mall with her. I wore a baseball cap to cover my shaved head, as well as baggy jeans and a long sleeved striped polo shirt to cover my pale skin and doughy-body. I did not look normal. My Mom went into a boutique store while I stood outside near a kiosk. A teenage girl, whom I did not know, approached me to ask if I shaved my head. I nodded and said, "yeah." "Can I touch it," she asked? "Um, yeah, I guess." I am not sure why I

said yes. I removed my hat. She rubbed my head and asked, “How come your head is so soft?” I had no idea what to say. I felt embarrassed; I choked up and almost broke out in tears.

Inhale. Exhale.

The concept of the normal body as a healthy body is a sociocultural construct and developed in the 19<sup>th</sup> century with the proliferation of medicine (Foucault, 1973). The treatment of an unhealthy body intended to restore the body’s health, as such, unhealthy bodies became aberrant and placed under the authority of medicine and the medical gaze. The difference between a cancer body and a *normal* body, historically, caused a public stigmatization of cancer, constituting cancer as—Goffman might say—a socially ‘spoiled identity’ in which patients manage cancer’s negative social meaning (Goffman, 1963). In this sense, the non-normal body, resulting from treating cancer, is a social signifier, signifying cancer’s denotative meanings for medicine and cancer’s connotative meanings for public. Cancer patients must (re)inscribe themselves in a discursive social system of differences and similarities (Derrida, 1988). When an adolescent patient presents or hides their non-normal body from public audiences, the adolescent makes a performance choice entrenched in, and circumscribed by, ideals of normal bodies as healthy bodies. The normalization of an everyday healthy-bodied aesthetic exposes a critical and performative matter of patient strategies for coping with cancer’s identity and cancer’s, all-too-often, non-normal body.

A narrative and performative model for coping with a cancer identity can expose a compulsory healthy-bodiedness shaping sociocultural perceptions of normal bodies as healthy bodies, and, by contrast, constituting unhealthy bodies as other bodies. The presentation and performance of a cancer patient’s body when telling a personal cancer story can contribute to the narrative analysis by exploring how patients performatively cope with the body’s transforming



materiality and the movement into a cancer identity situated against a healthy-bodied construct. As I discuss in Chapter 4, Butler's (1988) performativity claims hegemonic forces delimit bodies and bodily actions. The performing body becomes a linguistic conflation, a set of attributes signifying, and circumscribed by, various sociocultural and historical meanings and actions. For Butler, there is normative and resistant performativity. Normative performatives are stylized citations that reproduce past performances, wherein bodily actions rematerialize historical and institutional powers through the performing body. The hegemony involved in normative performativity circumscribes performative possibilities outside of its citationality. However, Butler's performativity allows for resistant performatives, wherein performance is non citational and has the potential to subvert the power in normative performativity and its "non-essentialized constructions of marginalized identities" (Dolan, 1993, p. 419), such as gender, sexuality, and race, to which I add health.

In this subsection, I explore adolescent cancer patients' presentations of their cancer bodies while telling a cancer story for public audiences. I exclude the survivor's video (Video 4) because she has been in remission for one year and does not present a cancer body. As I engage each video, I describe my experiences through viewing the presentation of their cancer bodies as it relates to memories of my cancer story. I record fragments of my cancer memories when triggered by an adolescent's performance of redress. I spotlight their liminal identities and their performances, to illuminate three options a cancer patient has during this liminal stage: (1) redress and reintegrate through the patient's internalization of schism and rejecting part of the self; (2) embrace schism and resist redress, performing monstrosity and one's role as an outsider; or (3) embrace a liminal identity as always belonging and not belonging, performing one's role as an outsider who has integrated. The stories that these teenage cancer patients tell are not solely

text, but also a matter of performances of coping with an identity as a cancer patient and its role in everyday life.

### **Video 1-Ovarian Cancer: Redress and reintegrate—covering/passing for normal**

The girl wears a gray beanie with a red rose pinned onto its side and near her left ear. I had several different beanies and two or three baseball caps when I had cancer. I liked beanies best. I would wear them low to cover my thin eyebrows. She also wears her beanie low enough to cover half of each eyebrow. She has drawn the other remaining half of her eyebrows. The beanie covers most of her ears, exposing just her lobes, where large shimmering gold earrings dangle. She wears a crimson red scarf that loosely hangs from her neck, which sits atop her cobalt blue shirt. Her makeup is heavy: bright red lipstick, blush, mascara, and eyeliner. Her aesthetic choices hide any signifiers of illness in her body. She looks *normal*. The presentation of her body is a performance choice, an attempt to pass as normal, as healthy, or at least not to appear unhealthy. Beanies and makeup are part of my cancer story. After the first few months of chemo, I had large dark sunken circles under my eyes. I looked like I was dying. I guess, I was dying. The dark circles bothered me, so my mom and sister started to apply concealer on my face before I would go outside. I eventually applied the makeup myself. I so badly wanted to look *normal*—gender norms be damned.

Her presentation of self is a normative performance of redress, one that rejects part of herself in order to seek reintegration. She uses covering and/or passing as a strategic act of coping, which was common for cancer patients like me. When she conceals bodily signifiers attributed to cancer, she avoids the public's gaze upon her non-normal body. Through passing and/or covering, she intends to restore a perception of her body's health. Cancer patients commonly use wigs, hats, caps, beanies, bandanas, shaved heads, makeup, and more to conceal

bodily signifiers associated with cancer. Like my cancer story, she covers signifiers of her non-normal body, attempting to pass for normal, or at least not to appear unhealthy. In a Goffmanian framework, seriously ill patients should attempt to pass for normal (i.e. reintegration); if not, completely avoid being in public (i.e. schism). Goffman (1959) suggested illness as a socially spoiled identity in which the sick perform a “discrepant role” (p. 41) by performing “non-person” (p. 51). When in public, the non-person avoids being noticed. In fact, “the role of non-person usually carries with it some subordination and disrespect” (pp. 151-152), suggesting cancer patients perceive a negative social value attributed to cancer’s identity. I, like this patient, responded like Goffman’s predictions of non-person. I felt ashamed of my non-normal body, which was especially true when in public spaces. Performing the discrepant role of non-person is then a passive coping strategy, avoiding stigma associated with being a non-person and having a non-normal body. Through redress, restoring the perception of the body to its everyday aesthetic prior to cancer, is consistent with this patient’s narrative of restitution.

### **Video 2-Hodgkin’s Lymphoma: Resisting redress—embracing schism’s monstrosity**

I click on the video link, and the image enlarges. I see a teenage girl. She wears a dark shirt, a black and white scarf, and very little makeup, though she has drawn on her eyebrows. Natural light enters the room from the window behind her left shoulder, partially shadowing her face, and highlighting the edges of her cheeks and cheekbones. Her cheeks are full and round, an effect often caused by high doses of steroids used in chemo protocols, but her cheeks do not stop her from smiling from ear-to-ear throughout the video. I had those same cheeks; my mom used to call mine, “chipmunk cheeks.” I hated those cheeks, and I hated the chemo hair. They socially marked me as different affecting my self-perception, my masculinity. My already young face

looked even younger, and I looked even less manly. I also wore my beanie low because it helped to make my cheeks seem less noticeable.

The patient's hair is light brown and sparsely grows atop her bald head, the long thin scraggly strands hang to her lower neck. I remember this hair too well from my own history with cancer. Though having this hair is typical for cancer patients who undergo chemo and/or radiation treatment, showing this hair so boldly is rare. Nobody told me my hair would still grow after it died or fell out. A few weeks after my brother first shaved my head, new hair grew back in sparse patches. The hair was thin and scraggly, my mom said the hair felt like baby hair. I hated it. I thought my hair looked weird, so my brother shaved my head every two to three weeks. I eventually bought an electric shaver. In most of the cancer videos I viewed, patients wear some sort of cap or wig or have a shaved head. This is the first video I have viewed in which a patient displays hair (resulting from chemo and/or radiation). Her choice to show public audiences her hair embraces the monstrosity of her body, a body I felt ashamed to have, a body I wanted hidden from the world, a body that scared me. By putting her cancer body on display, she performatively resists reintegration and embraces her schism as an outsider. She does not hide nor cover her body as Goffman's (1959) non-person would, she externalizes it. Her storytelling reveals a performance of active coping through embracing her non-normal body and any stigma of her cancer identity.

### **Video 3-Wilms Tumor: Covering not to pass, embracing a liminal identity**

I scroll down to select another video, I see "My Cancer Story:" [How I found out I have Wilms Tumor]. The video icon shows a young white thirteen-year-old adolescent girl smiling while sitting up in her hospital bed. I click on it. The image enlarges. Her smile is warm and sincere, and her face almost looks like a doll. She wears a lot of makeup. The heavy blush on her

cheeks warms the paleness of her white skin. She has drawn thick eyebrows, and the waxy sheen of her dark salmon colored lipstick matches the polo shirt she wears. The color is striking against the white sheets of her hospital bed and the cobalt blue wall in the background. I wonder why she is not wearing a hospital gown. Then I remember my pediatric nurses/doctors let me wear my own pajamas when I had extended stays in the hospital. She hides her bodily signifiers of illness, and other than her shaved head, she looks like a *normal* thirteen year-old-girl. Like I mention earlier, I shaved my head often when I had cancer, and I kept shaving it for years after cancer. Though a shaved head is a more typical look for a teenage boy than it is for this thirteen-year-old girl. Through her makeup and clothing, she partly integrates to an everyday social aesthetic. Through her shaved head she partly resists an everyday social aesthetic.

Telling a personal cancer story can depict coping strategies patients use to manage the uncertainty and uncontrollability associated with cancer, but more importantly can expose the complexity of coping with a cancer identity and its contingency to the body, bodily performances, and narratives. Through understanding these narratives as performances, we are able see how bodies create and are created by identities. In telling a cancer story, Frank's (1995) illness narratives expose an arrangement in which the storyteller's active and/or passive telling either can take control or relinquish control of the story, which is most evident when describing the uncertainty and uncontrollability associated with the disruption and disorder involved with liminality's chaos. I use Turner's (1982) social drama to show a four-stage approach to cancer stories, in which the fourth stage offers two options in the post-liminal stage: reintegration or schism. In addition, the fourth stage is contingent upon the third stage—redress—in which liminal performances constitute a changing identity. Butler's (1988) performativity informs the performance of redress, in which the presentation of self can expose how each patient copes with

her cancer body, either passing for normal and/or embracing stigma through normative and/or resistant performatives. In the performative act of telling their personal cancer stories, the adolescents in these videos constitute cancer identities for themselves and for others, interrogating those social discourses.

## **CHAPTER 6 CONCLUSION**

Perhaps, to my own perpetually liminal identity as an adolescent cancer patient, even many years after my diagnosis, I find myself resisting writing this concluding chapter. Part of me wants to keep this study in the liminal stage, part of me resists the structures of this form much as I resisted the advice of my doctors so many years ago. Being an adolescent cancer patient is not a phase that I moved through. It continues to impact virtually every area of my life, injecting uncertainty and liminality where a “normal” person might seek closure and certainty.

### **Summary and Major Contributions**

I began this dissertation by unpacking existing research regarding how adolescents cope during and after, a cancer diagnosis. This research indicates that adolescents cope with cancer differently than their older and younger counterparts because both cancer diagnosis and adolescence can throw identity into question. For many adolescents, the traumatic experience of cancer, which begins in such a crucial time of identity formation, extends well into their lives after their cancer is in remission. When responding to stress associated with cancer, adolescent patients often display troubling actions such as not taking their medication, smoking cigarettes, and resisting medical orders. From a purely medical health perspective these are maladaptive coping mechanisms, but from a developmental perspective these are often normal signs of identity formation as they forge their emerging adult identities. Despite these unique complexities, adolescent coping with cancer diagnosis has remained largely unstudied in health communication. Furthermore, what research adolescents have received has primarily been social scientific. This empirical approach has been generative, exposing several dimensions to explicate how patients situationally and/or personally cope with cancer’s uncertainty and/or uncontrollability through the patient’s passive and/or active management of problems, feelings,

and/or information associated with cancer. However, these approaches tend to understand the human subject as fixed and thus do not account for how coping situates in a fluid identity. I have supplemented this existing research with a more humanistic study that uses critical self-reflexive performative (auto)ethnography to explore performance and stories to make sense of these complex identities. My research indicates that coping with cancer, arguably for all patients but certainly for adolescent patients, is not simply a matter of asking: “How will I solve this problem?” “How will I deal with these feelings?” “How can I find meaning and value from having cancer?” “How will I manage uncertainties of cancer?” Coping with cancer is also a matter of asking: “Who am I?” “How will I adjust to these feelings that make me feel undone?” “What value and meaning do I have now that I have cancer?”

My main method for this study has been critical and self-reflexive performative writing. In Chapter 4, I foreground my positionality as a former cancer patient to illuminate my subjectivities and my cultural context through my personal experience(s) with adolescent cancer. I poetically texture my academic prose with my own cancer story and my present coping experiences to enact some of the performative challenges of telling an adolescent cancer story. This creative approach was sometimes fragmentary and incomplete. I did not attempt to give my reader information about my cancer as much as to enact and evoke how an adolescent cancer diagnosis threw (and continues to throw) my very sense of self into crisis. I also advanced a narrative and performative model for engaging with cancer storytelling not only as a source of data about the coping experience but also as a creative act of performance through which new identities form. This narrative and performative analytic understands the act of telling a cancer story as a matter of coping with a cancer identity through three interrelated dimensions: (1) telling a cancer diagnosis story is language in action; (2) there is an uncertain and an



uncontrollable narrative liminality for cancer patients, and particularly adolescent patients whose identities are in flux; and, (3) performed narratives of cancer diagnosis do not only reveal existing facts about diagnosis and coping, they also generate performative and narrative identities. A cancer diagnosis is a traumatic event, a biographical disruption that fractures identity, leaving in its wake the wreckage of one's personal narrative before cancer. Thus, a perlocutionary effect from the speech act of a cancer diagnosis is liminality. Patients embark on a chaotic, uncertain and an uncontrollable, narrative journey, wherein the performances of being a cancer patient shape a person's cancer identity.

In Chapter 5, I continued a critical self-reflexive performative writing as well as applied the narrative and performative analytic from Chapter 4 to analyze four videos<sup>49</sup> of adolescents telling a "My Cancer Story" online for public audiences. As I critically and reflexively engaged each performance of storytelling, I have placed our cancer stories in conversation with one another. I do not solely seek to give voice to these adolescent patients, but also to record our copresence and to seek the best dialogic representation I can. In addition, I have placed further attention on sociocultural effects narratively entrenched in cancer stories and a patient's presentation of self through the physical embodiment of telling one's personal cancer story. I analyzed these videos through several lenses, revealing new insight into coping through the contribution of a narrative and performative model for coping with cancer.

First, I used Frank's (1995) illness narratives (restitution, chaos, and quest) to explore the (un)controllable narration of, and narrative elements within, each cancer story. I have shown how each storyteller's usage of Frank's illness narratives can expose a storyteller's passive and/or

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<sup>49</sup> Video 1 (15-year-old with ovarian cancer); Video 2 (15-year-old with Hodgkin's lymphoma); Video 3 (13-year-old with Wilms tumor); and, Video 4 (19-year-old survivor of ovarian cancer)

active coping with one's cancer story through narration and language. Because Frank's restitution narrative is essentially the biomedical narrative, each story in its own way exposed the power of the biomedical narrative to circulate in these cancer stories (e.g. medical authorities control the story, military-like metaphors, and/or the chronological organization of the story: symptoms, diagnosis, treatment, and restoration of health). I have argued that Frank's illness narratives insert the uncertain and uncontrollable chaos of liminality between the pre-liminal and the post-liminal stages. This narrative arrangement exposed cancer stories as a matter of coping with the chaos patients experienced in liminality. In fact, three of the four videos display bodies that are still in the liminal stage. Liminality and its relationship to identity, to performance, and to narrative exposes an embodied performative dimension within Frank's largely textual narrative framework.

Second, I have further argued that Turner's (1982) concepts of liminality and social drama (breach,<sup>50</sup> crisis,<sup>51</sup> redress,<sup>52</sup> and reintegration<sup>53</sup> or schism<sup>54</sup>) along with Butler's (1988) concepts of performativity and the relationship between the body, bodily, action and discourse can extend Frank's (1995) illness narratives from three stages to four stages, connecting the liminality associated with Turner's (1982) redress stage to performance and identity in which the outcome is reintegration into social fabric or schism from it. Performativity further enforces the strength of performances of redress as a matter of identity (Butler, 1988). The performative

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<sup>50</sup> Cancer first *breaches* the body's normative abilities.

<sup>51</sup> The body reaches *crisis* at diagnosis, causing liminality.

<sup>52</sup> Medical treatment *redresses* the liminal body's crisis.

<sup>53</sup> *Reintegrating* the redressed body into society as a cancer patient and/or as a survivor of cancer.

<sup>54</sup> *Schism* the redressed body from everyday social life.

analytic supplements the narrative analysis, demonstrating how each patient presents the redressed self as a performative way of coping with her cancer body, either passing for normal or embracing stigma through normative or resistant performatives. For these patients, the liminal identity in redress has three options for moving from redress to reintegration or schism: (1) redress and reintegrate through the patient's internalization of schism and rejecting part of the self; (2) embrace schism and resist redress, performing monstrosity and one's role as an outsider; and, (3) embrace a liminal identity as always belonging and not belonging, performing one's role as an outsider who has (partly) integrated. Because I used a performative analytic to supplement the narrative analysis, I also exposed how these adolescent patients constituted their cancer identity in the arrangement and performance of telling their cancer story.

Storytellers socially situate their stories and performances of storying with or against normative narratives and performatives. Frank's (1995) illness narratives are a standard approach to evaluate illness stories. Turner's (1982) social drama adds needed layers to our understanding of illness narratives and should be a narrative and performative model to analyze future videos or live performances, wherein cancer patients and former cancer patients tell personal cancer stories. This dissertation thus contributes a new model for coping through a dramatic framework for illness narratives that not only spotlights the story but the embodied act of storytelling as an approach to analyze coping with cancer's uncontrollability and uncertainty.

### **Directions for Future Research**

#### **Performative and Narrative Coping in Health Communication**

A narrative and/or performative approach to explore coping with cancer facilitates the expansion of ways in which health communication investigates coping with cancer. Personal narratives of cancer can function as a site to investigate existing coping strategies depicted in a

patient's story. For example, my cancer story revealed how I coped with cancer's uncertainty and uncontrollability through using a proactive meaning-focused coping strategy. I consciously attempted to control my good white blood cells to eliminate my cancerous white blood cells. Additionally, patients' stories in videos three and four both employed illusory control coping strategies as they released control of their stories to a predetermined fate through God's will. Besides depicting coping strategies, the narration, arrangement, and language used in cancer stories expose a dimension of (un)controllability often overlooked in coping research. A narrative focus on coping with cancer has the potential to supplement health communication's approaches to coping with cancer by adding the (un)controllability evident in restitution, chaos, and/or quest narratives undergirding these cancer stories. The performative analytic and the focus on liminality as redress can further the exploration of coping with a cancer patient identity by expanding the stages of Frank's (1995) illness narratives through Turner's (1982) drama. Liminality is more than some stage patients move through, but a redress and (re)formation of identity. The concept of coping with one's transforming identity in being and becoming a cancer patient reveals a fluid subject. Humanistic approaches to identity rather than social scientific approaches<sup>55</sup> can unpack identity as socially situated and subject to narrative and performative forces and as never fixed always fluid. The narrative scholarship in health communication, though less directly focused on coping with cancer, can function as a bridge for performance scholars to cross into health communication by critically exploring coping with a cancer identity and coping through performing one's illness story.

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<sup>55</sup> Many social scientific approaches to coping with cancer investigate identity through scales measuring self-efficacy and self-reliance.

## Implications

The broadest implication this dissertation has for performance studies is that coping with cancer is a performative matter of narrative identity and the performance of telling a cancer story is an act of coping. Thus, coping with a cancer identity—or for that matter any illness identity—is a performative act, evident in a patient’s normative and resistant performatives. In a more specific sense, Turner’s (1982) dramatic structure, and the liminality involved with redress not only adds a more nuanced framework than Frank’s (1995) illness narratives but adds an emphasis on identity (re)formation through performing redress. Personal narratives of cancer “articulate their reflexive and emergent qualities to be restoring/creating identity and social critique” (Carlin & Park Fuller, 2012, p. 20). The performative act of coping with a cancer identity is a cultural act (Lionnet, 1989; Alexander 2008). A critical approach to cancer identity can spotlight the body as born in a sociocultural world entrenched in privileged illness narratives and performatives that (re)construct healthy bodies as normal bodies and unhealthy bodies as abject bodies. There is a compulsory healthy-bodiedness in society, an aesthetic that underlies the everyday body, and exposes the force of the biomedical narrative of restitution: patients must seek restoration of the unhealthy body to reintegrate into the social norm, otherwise the unhealthy-body, or the abject body, socially schisms as outsider and as non-normal. These social consequences act as forces delimiting performances and affecting how one copes with cancer. The critical approach to cancer identity can demystify how power operates through sociocultural forces such as narratives and performatives of cancer.

A focus on performing narratives of cancer is not new for performance studies. Solo performances, like Lobel’s *BALL* (2008) and Park Fuller’s *A Clean Breast of It* (1995), put the performer’s body and cancer story on stage for public audiences. Their cancer stories and the

stories I analyzed in Chapter 5 situate in the personal trauma of having, or having had, cancer. Telling a personal cancer story is a performative act of coping with that trauma—an aesthetic strategy that makes sense of, and meaning<sup>56</sup> from, the traumatic event (Carlin & Park Fuller, 2012; Langellier & Peterson, 2004). As mentioned in Chapter 3, the catharsis one experiences from autobiographical or confessional ethnography is important for the author/ethnographer, but still can lack a dialogism (Terry, 2006). Solo performance of one’s personal narrative of trauma receives similar critiques such as it is a matter of the performer’s ego, seeks catharsis of trauma, and/or seeks self-healing. “Despite the suggested critiques of *solo performance* as a narcissistic act of self-indulgence and narcissism” (Alexander, 2008, p. 91), solo performance is an act situated in, and bound to, society and culture. Performing these cancer stories has the potential to be more than merely a coping strategy but also a source of sociocultural change, which I discuss in more detail in the next section through possibilities of a narrative and performative analytic.

### **Extending a narrative and performative analytic**

The narrative and performative approach used in this dissertation can reveal relationships between and among the performance of telling a cancer story, a patient’s identity, society, and culture. Coping with cancer’s narrative and performative identity opens the door to possibilities for future critical and/or qualitative research. To name a few: (1) building a body of (subgenres of) personal narratives of cancer in health communication; (2) new media as sites of cultural expression through which to explore aesthetic conventions in and of narratives and performatives used to perform one’s cancer story; and, (3) a direct ethnographic engagement through workshops using performance ethnography with medical professionals; (4) creating

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<sup>56</sup> Performance as an aesthetic strategy to cope is a secondary meaning-focused coping strategy (see Chapter 2).

conspicuously aesthetic, staged performances to share with specific audiences; (5) creating oral interpretation workshops for medical professionals.

(1) Future studies exploring the act of telling a cancer story as an act of coping with cancer's identity should apply the narrative and performative analytic to build subgenres of personal narratives of cancer and the performative act of telling a cancer story. As a body of knowledge, the aesthetic strategies patients use to cope through the creative arrangement in the performative act of telling a personal cancer can establish a body of qualitative research on coping with cancer's identity in two overarching ways. First, a subgenre of personal narrative of adolescent cancer can give voice to the marginalized positionality in being an adolescent cancer patient as well as existing marginalized positionalities of adolescent cancer patients. As mentioned in Chapter 4, the aesthetic design in the pediatric hospital that treated me communicated to much younger patients. Personal stories of adolescent cancer, like my cancer story, speak to the experience of becoming and being an adolescent in the world of pediatric cancer. A subgenre of personal narrative of adolescent cancer can expose the effects of marginalization through the similar/different aesthetic strategies adolescent patients use in telling a cancer story. A further focus on adolescent identity should orient its attention toward intersections of identity: gender, ethnicity/race, sexuality, ability, types of cancer, and more. Moreover, a cancer identity is not merely a matter for adolescents, and a focus on other age groups and their intersectional identities can further develop a complex body of research for personal narratives of cancer. Second, a body of research on personal narratives of cancer as subgenre through types of cancer diagnoses can expose cancer cultures that produce and reproduce sociocultural forces affecting narratives and performatives. For example, when looking at adult cancer videos online, I ran across several breast cancer videos using similar

aesthetic strategies to perform their cancer stories. These cancer stories are an expression of (breast cancer) culture. Ehrenreich (2001) has shown breast cancer culture through its representations in “websites, newsletters, support groups, national organizations, and races for the cure” (Langellier & Peterson, 2004, p. 191). She has claimed the survivor narrative, consistent with Frank’s (1995) restitution and quest narratives, is pervasive in breast cancer culture. As a dominant cultural thread, the survivor narrative can delimit the act of storying breast cancer for patients who, like the patients in videos two and three, are still experiencing the chaos in the liminal stage. The narrative and performative analytic can inform these breast cancer stories and other subgenres of personal narrative of cancer.

(2) New media can function as sites for further narrative and performative excavation (Gray, 2012; Levan & Chvasta, 2012; Myers & Rowe, 2012), having the potential to uncover aesthetic similarities and differences in (digitally mediated) performances. New media performances are cultural expressions, partly (re)constructing cancer cultures and subgenres of personal narrative of cancer. As mentioned in the above paragraph, several of the adult breast cancer stories I came across online shared similar aesthetic strategies, wherein performers silently told cancer stories through pre-written text (the patients sat or stood, staring at the camera, using a small stack of papers to tell their cancer stories, performers would toss a paper to the floor one after the other) meanwhile, “Fight Song,” by Rachel Platten (2016) played the entire time. Their shared aesthetic strategies expose how digital spaces allow for new possibilities in the performance of telling a cancer story while privileged cancer narrative elements, such as the metaphoric language of “fighting,” continue to circumscribe the story. Digital media enacts new ways in the cultural transmission of performance, a performer’s



presence,<sup>57</sup> and underlying power through the relationships among storyteller, the story, the performance, the viewer, and the medium. This relationship co-creates a (digital) presence through a new here and a new now that can transcend the live body (Coonfield & Rose, 2012). The various modes of digitally expressing cancer are cultural expressions of cancer and sites for critical evaluation of narratives and/or performatives of cancer.

The communicative practices for expressing cancer through new media can function as sites to explore the role narratives and performatives play in (re)producing cancer cultures. Pediatric cancer, like breast cancer, has received considerable public attention that partly cultivates a pediatric cancer culture. As Ehrenreich (2001) has shown, various modes for cultural expression of breast cancer (e.g. breast cancer organizations, websites, advertisements, races for cure, et cetera) partly (re)construct breast cancer culture. The (re)construction of pediatric cancer culture parallels that of a breast cancer culture through sharing Ehrenreich's modes for expressing breast cancer. Since Ehrenreich, new media has further increased outlets for cultural expression, spinning a more complex web on which narratives and/or performatives of cancer circulate. For example, pediatric cancer has a host of organizations<sup>58</sup> that have websites, races for cures, advertisements for donations, support groups, the month of September is pediatric cancer awareness, and the color gold and gold bracelets symbolize pediatric cancer. The circulation of narrative and performative representations within these practices constitutes a power through privileging representations in which new media aids circulation. For example, St. Jude's

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<sup>57</sup> Digital media makes the absence of these performers present through the performer's digital trace and the viewer's experience of aura.

<sup>58</sup> Pediatric organizations such as St. Jude's Children's Hospital, Leukemia and Lymphoma Society of America, National Pediatric Cancer Foundation, Make-A-Wish Foundation, and more place ads, hold races, have websites for information of pediatric cancer that partly create a pediatric cancer culture.

Children's Hospital is not just a hospital, it is an organization doing extensive research in pediatric cancer. St. Jude's Hospital is also a well-known public entity through its television ads, website, races for cures, its Twitter, Instagram, YouTube, and Facebook. New media outlets offer ways in which organizations like St. Jude's partly (re)construct pediatric cancer. Analyzing narratives and performatives of pediatric cancer culture through new media outlets can further expose privileged narratives and performatives (re)constructing the world of pediatric cancer in which adolescents find, or cannot find, themselves. Like breast cancer stories situate within or against breast cancer culture, adolescent stories situate within or against pediatric cancer culture.

(3) The limitations from my performative autoethnographic approach have made me consider the potential to extend future work through direct ethnographic engagement. To protect adolescent cancer patients, I have avoided direct interviews with them, which hindered dialogism in this research. These adolescent patients are minors. Furthermore, adolescence is already a trying time in one's life, and adolescents recently diagnosed with cancer are coping with multiple traumas related to cancer. I believe the physical presence of a researcher during this sensitive time is intrusive. I prefer to give adolescent patients and their families space to cope with cancer. Therefore, there are no field notes, no interviews, and no participant-observation from live interaction, but only through engaging bodies in a digital space. This removes the live body from my analysis, hindering my experience of each storyteller's live presence, with which I must engage through trace effects and an aura developed in my relationship to the video record. Direct ethnographic engagement can continue to explore adolescent cancer while maintaining a respect for the privacy of adolescent cancer patients through workshops with medical professionals.

(4) One way I hope to extend this project is through the performance of personal narrative. Like "members of [other] oppressed groups" I have "found few texts reflecting

[adolescent cancer] experiences” which motivates my desire to create and share “performances of personal narrative” (Shaffer, Allison, & Pelias, 2015, p. 196). The strength of personal narrative led me to conceptualize future staged performances of teenage cancer stories in two ways. First, a site-specific performance that uses storytelling as both a coping strategy for patients in pediatric hospitals and targets audiences who should hear these patients’ stories. “Welcome to Cancerland,” the working title, would be a traveling show and site-specific to pediatric hospitals, using personal narrative as a method through which hospitalized pediatric cancer patients would write and perform their stories of cancer. The intent of performing in pediatric hospitals is to attract an audience that includes physicians, nurses, and other medical staff, so they can hear the stories of illness and watch how pediatric patients embody their illness stories. As Langellier and Peterson state, “For storytellers, the narrative is an opportunity to exert agency and empowerment in a disruptive and dehumanizing experience; for audiences the illness narrative negotiates the anxieties of their temporary able-bodiedness and the specter of death” (Langellier & Peterson, 2004, p. 190). In speaking back to hospital employees through performance of cancer narratives, I hope to create a dialogue surrounding adolescent cancer experiences, potentially affecting change. Staging performances of personal narratives of cancer can help adolescent cancer patients cope with cancer through the act of performing their own stories and increase audiences’ awareness of illness experiences of these teenagers with cancer.

(5) I also believe that the text/ transcription of adolescent cancer stories can function as workshop scripts for performers who do not have, or have not had, cancer. The performance of someone else’s cancer story is epistemic, a way of knowing through the interpretation and embodiment of the story through which performers learn empathy and a new way of understanding the other (Pelias & Shaffer, 1999; Fine & Speer, 1977; Turner, 1982;

Conquergood, 1985; Langellier, 1989, Denzin. 2003). In future research, I would like to use the performance of stories, like those I have analyzed above, as a tool to work with oncologists and other medical professionals who work with adolescent cancer patients. The purpose of these performances would not be to create a “show” for a public audience but to help add some nuance to the ways in which medical professionals approach diagnosing in general and adolescent cancer patients in particular. These workshops move medical professionals from viewing cancer stories, such as “Welcome to Cancerland,” to performing cancer stories. Pelias and Shaffer (1999) assert an empathic process using “recognition,<sup>59</sup> convergence,<sup>60</sup> adoption,<sup>61</sup> empathy and performance<sup>62</sup>” (p. 107) to perform someone else’s story. Shaffer et al. (2015) suggest the practice of and pedagogy behind performing aesthetic texts like personal narrative “theorize the relationships between self, other, and culture” (p. 197). Thus, workshops for medical professionals, centered around the pedagogical value of performing cancer stories, have the potential to instigate an empathic and kinesthetic response through a dialogic engagement with an adolescent’s cancer story. The potential directions of a narrative and performative analytic

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<sup>59</sup> Recognition is the first stage of the empathic process, wherein performers attempt to understand the complexity of the other’s point of view.

<sup>60</sup> Convergence is the second stage of the empathic process, wherein performers begin to identify with the other through projective identification (the performer sees herself in the other’s situation) and adjustive identification (the performer relinquishes control to the other, adapting to new ways of seeing).

<sup>61</sup> Adoption is the third stage of the empathic process and is contingent on the previous stage of convergence. If convergence is projective identification, then adoption is self-dominated. If convergence is adjustive, then adoption is other-dominated.

<sup>62</sup> Empathy becomes a tool to stage performances of cancer stories, guiding a performer’s choices for staging and representing the other. In rehearsing the performance, performers not only repeat words authored by the other, performers embody their emotional connections in the telling.

and the performance of cancer stories situates in its own liminal space and the possibilities that exist between performance studies and health communication.

### **Final Thought**

I sought to understand narrative and performative forces (re)shaping cancer's materiality and discursivity with which patients' cope. I also sought to understand myself, my coping, my cancer identity through my relationship to others. Perhaps, in Frank's (1995) sense, this dissertation is my manifesto, my automythology, a quest narrative in which I hope to improve coping for adolescent cancer patients, and a way in which I cope with (surviving) cancer through writing. In Turner's (1982) sense, I am stuck in the liminality of my (former) cancer identity—a body restored and reintegrated, but an identity that presently experiences its past. I am not sure when I started to feel like a cancer patient, but I know I still feel like one.

I tilt my head down and to the right,

Bringing a cigarette to my lips.

I raise the lighter to reach the cigarette's tip,

Rolling my thumb to spark its flint.

Deep inhale.

Slow exhale.

Repeat.

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## **VITA**

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