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**TRIUMPH OVER ADVERSITY: A QUALITATIVE STUDY OF NARRATIVE,  
COPING AND EXPERIENCE IN INDIVIDUALS DIAGNOSED WITH CANCER**

A Thesis in

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by

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## Abstract

The increased occurrence of chronic illness has created a need to study the experience of illness from the patient perspective. Current medical training and education does not typically incorporate the patient experience of illness. Learning about patient perspectives is even more important in disease such as cancer which has a tremendous psychosocial impact on patients. Patient narratives are an appropriate means of studying patient experience of cancer. More than ever, people are writing accounts of the experience of illness and treatment and patients are turning to these narratives for anecdotal information about particular illnesses and their treatments, conventional and alternative (Hawkins, 1999). This study takes a qualitative approach to studying cancer narratives of 21 patients to understand the patient experience of disease as well as examine the role narratives play in the patient experience of disease. Distinct features of the patient experience of cancer were identified by the qualitative analysis. Features of the cancer experience included the impact of diagnosis, treatment, and prognosis on the cancer experience, perceptions of the etiology of cancer, coping mechanisms such as social support and spirituality, reactions to the health care system, and metaphors for describing the cancer experience. Results of this study suggest that personal cancer narratives—written, read, told, and listened to—can be highly useful for patients coping with a cancer diagnosis. The results also suggest that narratives might be an important public health tool for the dissemination of cancer related information.

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Cancer go away - go far away from me,  
I don't want to find you - hiding in my body.  
Go far away from here, this is not your home,  
Please go find a new place that you can roam,  
Maybe in a meadow or a big ol' pile (Lipscomb, 2008)

The above described poem was posted on an online blog by a patient who was diagnosed with breast cancer for the second time. The poem was listed as “A poem about cancer: Cancer Go Away!” (Lipscomb, 2008) Though the poem is simple in its wording, it captures the feeling of dissent experienced by the millions of patients who are diagnosed with cancer all over the world. I want to dedicate this thesis to all the individuals who are diagnosed with cancer and face the challenges of their diagnosis, treatment and survivorship. It takes courage to face the multiplicity of fears that hound the minds of the cancer patients. I want to acknowledge the participants who chose to be part of the “messages in cancer communication” study, which was the data source for this thesis. Their insightful and rich narratives and responses demonstrate that the human spirit still finds ways to express itself even in disease and infirmity. I want to acknowledge my grandfather who is currently undergoing chemotherapy for lung cancer. I pray that he maintains his dignity through one of the most difficult medical treatments. I also want to dedicate this work to my friend Sandeep who passed away from brain metastasis when I was in medical school. Sandy, your life was an important one; your struggle with cancer gave me the inspiration to learn more about the cancer experience. I

promise to tell the world about your story.

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## **Chapter 1**

### **Introduction**

Holi, also called holikotsava is a very popular festival observed throughout India. It is especially marked by celebration with colors and dance and by all sections of society. The mythological background of this festival is a story, which is rooted in the tradition of good versus evil. There was a mighty demon king named Hiranyakashyapu who had become very proud after winning all the three worlds of heaven, earth, and hell. He thereafter enforced a law that everybody would worship him instead of gods and deities. His little son Prahlad, however, refused to accept his commands and continued to worship Lord Vishnu with complete devotion. Enraged by his son's disobedience, he ordered his soldiers to throw him down a hill. Prahlad, who was firm in his faith in Lord Vishnu, prayed fervently for his protection. Lord Vishnu rescued him at the last moment. Flustered by this news, King Hiranyakashyapu invoked the help of his evil sister, Holika. Holika had a divine gift that she could walk through fire unharmed. Holika convinced Prahlad to sit on her lap. She then started a fire at the place where she sat in order to burn Prahlad to death. However, the gift worked only if Holika entered the fire alone or she would perish. Thus, blessed by Lord Vishnu, the child Prahlad remained unharmed but Holika got burnt and died instantly. Holi is thus the victory of good (demonstrated by Prahlad's depth of faith in God) and the failure of evil by the death of the evil aunt Holika, after whom the festival is named.

Telling this story is a popular cultural tradition and is commonly narrated in



families and religion classes in schools in India. I, however, overheard this story being narrated in a Pediatric inpatient ward. While the medical internship can be very stressful, one of the liberties it gives the medical student is the opportunity of having prolonged interaction with patients and their caregivers. In this case, it was a mother narrating the story about Holi to her sick child diagnosed with malaria. The evil in the story was attributed to the disease and the mother called on her child to show the depth of faith in God like Prahlad did, and she would thus be cured by the Lord. I wanted to share this story which was buried in a small pocket of my consciousness to introduce my thesis which is a study of stories related to the disease of cancer.

Illness often calls for stories and story-telling (Frank, 1995). The analysis of illness narratives is critical to enhance our understanding of the patient experience of illness and their treatment needs. This chapter introduces such a study in terms of reasons for my own interest in this topic as well as the need for this research. I will also briefly introduce the methods employed to conduct the study and describe some limitations of this study.

### **Why Study Illness Narratives?**

Disease interrupts life, and therefore illness means that the individual has to live with perpetual life interruption (Frank, 1995). In order to deal with this life interruption, human beings construct stories that can have many functions. Narratives are an appropriate means of examining issues of health and healing because they wrestle with complexities that face medical patients. Identity construction, order and disorder, autonomy and community, fixed and fluid experiences are all constructed and communicated through illness narratives (Harter, Japp & Beck, 2005).

Narrative is a fundamental human way of giving meaning to experience. In both telling and interpreting experiences, narratives mediate between an inner world of thought-feeling and an outer world of observable actions and states of affairs.

(Garro & Mattingly, 2000, p. 1)

Stories can provide a powerful medium for learning and gaining understanding about others by giving the researcher a context for insights into what one has not personally experienced (Kleinman, 1988).

Even though illness disrupts life, illness can actually be an opportunity for individuals to pay more attention to their body's signals, and thus learn something from illness that helps to bring the individual back into alignment with their potential wellness (Rossman, 1989). Storytelling can be viewed as a form of communication that can help people successfully cope with and reframe illness and thereby create the paradoxical possibility of being "successfully ill" (Frank, 1995). Brody (1987) contended that "storytelling as an activity is central to medicine" (p. 12) and that "suffering is produced, and alleviated, primarily by the meaning that one attaches to one's experience (p. 5). Also the "primary human mechanism for attaching meaning to particular experiences is to tell stories about them" (Brody, 1987, p. 5). Narratives serve as a method of working through the anguish and suffering brought on by a life-threatening illness. Individuals ascribe meaning to illness and health in several senses such as personal, social and cultural (Kleinman, 1988). Narratives can provide an understanding of the experience of illness through the rich descriptions they impart, and the wealth of detail that emerges.

### **Narratives in Medicine**

Physicians have come to acknowledge the contributions of narrative study to

medicine. Physician Brian Hurwitz (2000) describes clinical encounters in terms of narrative as, “one way of understanding clinical encounters is to see them as complex processes of story construction and exchange, where fragments of experience in different stages of narrativity are elaborated and pieced together” (p. 3). Greenhalgh and Hurwitz (1999) describe the importance of studying narratives in clinical encounters because narratives can assist physicians in the dimensions of patient diagnosis, therapy and patient education. From having the ability to encourage empathy and promote understanding between clinician and patient, narratives also encourage a holistic approach to management and are intrinsically therapeutic or palliative (Greenhalgh & Hurwitz, 1999). This study argues for an in-depth study with a thematic understanding of narratives to inform the medical community and health care providers about themes and elements of interest in cancer patient narratives.

### **Importance of Cancer Narrative Research**

Cancer is the second most common cause of death in the United States. The American Cancer Society reports that 7.6 million people died from cancer in the world during 2007. Along with the morbidity, mortality and resources that the disease consumes, cancer creates tremendous psychosocial issues on patients and caregivers (Cohen, Cullen, & Martin, 1982). Research indicates that the incidence of suicide in cancer patients can be equal to the incidence in the general population, or up to 2 to 10 times as frequent (Hem, Loge, Haldorsen, & Ekeberg, 2004). It is important to note that the actual incidence of suicide in cancer patients is probably underestimated due to the reluctance of reporting the suicide by the patient’s families (Holland, 1982) as well as due to lack of ways to measure the statistic (Pessin, Amakawa, & Breitbart, 2010). The

suicide risk is highest in the first months after diagnosis, and there is a significant decrease in relative risk over decades (Hem et al., 2004). We thus see that cancer is a unique disease not only in physical terms, but also psychosocially. Thus, the study of narratives related to cancer is imperative because psychosocial interventions in this field promise to help alleviate the suffering of millions of cancer patients worldwide.

### **Patients Learning from Illness Narratives of Other Patients**

More than ever, people are writing autobiographical accounts of their experience of illness and treatment. These illness narratives are sometimes referred to as pathographies or autopathographies (Hawkins, 1999). Increasingly patients are turning to these narratives for anecdotal information about particular illnesses and their treatments, conventional and alternative (Hawkins, 1999). “Pathographies not only articulate the hopes, fears, and anxieties so common to sickness, but they also serve as guidebooks to the medical experience itself, shaping a reader's expectations about the course of an illness and its treatment” (Hawkins, 1999, p. 4). Pathographies are thus an authentic resource of patient attitudes and assumptions regarding all aspects of illness. A systematic study of patient narratives can help bring to light the concerns and experiences of the patient relating to their illness.

Narratives have the potential to be used in medical practice as well. Describing psychosocial concerns takes time for patients, and physicians are bounded by time constraints of the medical institution they are working in. The physician is trained to make use of the consultation time to elicit important information related to physical diagnosis and past medical history of the patient. Therefore the psychosocial aspects of the patient get put on the backburner. Patient narratives can be especially useful to

physicians since physicians are given less and less time to get to know their patients but are still expected to be aware of their patients' wishes, needs, and fears (Hawkins, 1999). Patients can articulate their psychosocial concerns in the form of a narrative or autoethnography in their own time outside the medical consultation. Subsequently, doctors can read these patient narratives in a much shorter duration of time than the time it would take to listen to the patient articulating their psychosocial concerns for the first time. Thus patient narratives hold important potential in medical practice.

### **Problems in Current Medical Education**

“The patient’s own story is vital.” This is the first sentence of the section on listening in the chapter on history-taking featured in Macleod and Douglas’s clinical examination text book (2006, p. 6). Medical science has definitely come to a consensus about the importance and value of the patient’s story and the patient’s description of disease. The latest edition of *Harrison’s Principles of Internal Medicine* (2008) reiterates this fact for us. Guidelines for patient history taking are described as: The patient should, at some early point, have the opportunity to tell his or her own story of the illness without frequent interruption and, when appropriate, receive expressions of interest, encouragement, and empathy from the physician. Any event related by the patient, however trivial or seemingly irrelevant, may provide the key to solving the medical problem. In general, only patients who feel comfortable will offer complete information, thus putting the patient at ease to the greatest extent possible contributes substantially to obtaining an adequate history (Anthony, 2008, p. 1).

However, the value of narrative, for many clinicians, is more theoretical than applied. Even the Harrison’s textbook emphasizes patient narrative and effective patient

communication only initially before “devoting the next two thousand pages exclusively to organ systems and biochemistry” (Coulehan, 2003, p. 91). Thus there is a huge gap in the ways that patients and physicians are educated to understand and describe their symptoms or the experience of disease. The Stedman’s medical dictionary (2008) defines clinical history as “a narrative or record of past events and circumstances that are or may be relevant to a patient's current state of health” (p. 817). It describes medical history taking, both in a formal and informal sense. Informally, medical history taking describes an account of past diseases, injuries, treatments and other strictly medical facts. It is noteworthy how strong an emphasis is placed on the importance of medical facts with the use of the word “strictly” even in the informal sense. Further, medical history taking is described more formally as a comprehensive statement of facts pertaining to past and present health gathered ideally from the patient by directed questioning and organized under the specific headings. The major one is the Chief Complaint (CC) which is a brief statement of the complaint or incident that prompted medical consultation. A History of Present Illness (HPI) which is a detailed chronologic narrative as much as possible in the patient's own words, of the development of the current health problem from its onset to the present. Past Medical History (PMH) constitutes prior illnesses, their treatments, and sequelae. Social History (SH) consists of marital status, past and present occupations, travel, hobbies, stresses, habits and use of drugs. It also includes Family History (FH) and review of symptoms (ROS).

Even though the Stedman’s medical dictionary is the gold standard for medical practitioners around the world, to make sure that this information should not be the bias of one publication, I reviewed another reputable medical dictionary for the meaning of

the same term. Mosby's medical dictionary (2009) defines health history (in nursing and medicine) as a "collection of information obtained from the patient and from other sources concerning the patient's physical status as well as his or her psychological, social, and sexual function" (p.18). The health history subsequently provides the practitioner a database on which a diagnosis, a plan for management of the diagnosis, treatment, care and follow-up of the patient may be made (Mosby, 2009). Mosby (2009) describes the medical history to have two parts; the first part of the history describes the chief complaint, which is the primary reason that brings the patient to the hospital. In the first part "the patient's words serve as best description and can be quoted." In the second part of the history accounts of previous illnesses and health-promotion behaviors, allergies, transfusions, immunizations, screening tests, and hospitalizations are recorded as well as an occupational history, social history and sexual history. A review of systems may follow or be incorporated into the health history.

Note that Mosby's definition, even though it mentions that the patient's words serve as the best description and can be quoted, still lays down strict guidelines for the clinician as to the purpose of the medical history taking. In fact the medical student is primed from the very beginning of his/her education about the specificity of the history taking process. The first sentence in Harrison's Principles of Internal Medicine (2008) states that, "The written history of an illness should include all the facts of medical significance in the life of the patient" (p.1). The Bates guide to physical examination and history taking (2007) opens the health history chapter with a directive to the medical student which directs the student in the following way,

As you talk with the patient, you must learn to elicit and organize elements of the

patient's health. During the interview this information will not spring forth in this order! However, you will quickly learn to identify where to *fit in* the different aspects of the patient's story (Bickley, Szilagyi, & Bates, 2007, p.6).

Again the emphasis is on "fitting in" the patient's narrative to what the physician is looking for (i.e. chief complaints, past health history etc.). Physicians miss out important contextual information because they are taught to avoid listening to the patient's story as he/she narrates it, but rather focus on what medical information they can extract from the patients narrative.

Lay patients without medical training most likely do not know the meaning of "chief complaints" or even what physicians expect when talking about "the history of present illness" or "past medical history." Human beings describe their experience through symbols and language (Burke, 1950). More importantly human beings describe and communicate their experience through stories. All human cultures rely on storytelling and metaphorical expressions to achieve social integration (Bury, 2001). Fisher (1987) goes further and calls us *Homo narrans*, thereby implying that we as humans are inherently story-telling organisms. Gellner (1992) argued that narratives can convey and constitute an 'infinite reservoir of meaning and comprehension'. Thus the patient's story might also have important clues to the patient experience of disease and important contexts for the symptoms experienced by the patient.

To achieve an accurate and in-depth understanding of the patient's experience, it is important to study the stories or narratives from the perspective of the patient suffering from the disease along with doing a careful in-depth analysis of the narratives. If patients are increasingly turning to these illness narratives for anecdotal and other information



(Hawkins, 1999), it is important to study the narratives that patients find appealing and not appealing to structure guidelines for writing these narratives. Also, these narratives can serve as a tremendous resource to understanding patient experience, disseminating health information as well as narrative interventions for prevention and healing of medical conditions.

### **Purpose of This Study**

The current study has a range of goals, all of which involve an in-depth look at the content of cancer narratives and participant responses from different perspectives. Firstly, this study will attempt to elucidate the patient's experience of cancer as described in the narratives. Illness narratives represent a means of understanding what the body experiences through cancer, as has been emphasized in past research, a way of recuperating what may be considered lost (Frank, 1995). It may be hard to explain suffering, but one can learn to comprehend this phenomenon through such close analyses of patient narratives (Schweizer, 1995). Furthermore, understanding the patient's experience of disease is the initial step a doctor takes toward improving the therapy to benefit the patient's medical condition.

Secondly, the study will try and understand the differences between stories that patients report as worthy of sharing compared to those not to be worthy of sharing. A review of illness narrative research reveals that patients have not been asked to report narratives as worthy of sharing or not worthy of sharing prior to this research study. The differences in content of these stories may give insights regarding cancer-related information that is conveyed in narratives, as well as possible persuasive elements of these narratives. The study will include patient responses and the reasons reported by

cancer patients about the stories they found worthy of sharing or not sharing. Studying these persuasive elements may inform interventions that make use of patient narratives as a strategy aimed to communicate information about cancer screening, diagnosis and treatment (Kreuter, 2007). The study may thus inform health care practitioners about the importance of illness narratives and the various impacts that narrative study can have on the practice of medicine.

The study will also describe what patients want to read in an illness narrative about cancer. Illness narratives can shape a reader's expectations about the course of an illness and its treatment (Hawkins, 1999). Thus, this study will inform the medical and social science fields about the content of the cancer narratives as well as what patients want to read in those narratives. Many large health care organizations (e.g. Mayo Clinic) are now using patient narratives as guides for recently diagnosed and incoming patients. These patient narratives serve as testimonials for the health care organization along with providing a frame of reference for the disease experience and the treatment experience at that health care organization. This study will hope to inform what narrative content patients find worthy or sharing and what content they do not find worthy of sharing.

Lastly, this study will aim to investigate the perceived benefits of writing or sharing cancer narrative as well as listening or reading cancer narratives. The literature describes various health benefits of story-telling or writing (Pennebaker & Seagal, 1999) and story-listening or reading (Sunwolf & Frey, 2001). There are now many examples of how narratives have been used therapeutically in healing contexts ranging from chronic conditions like asthma and cancer to cases of severe trauma (Sunwolf & Frey, 2005). This study will thus provide insight from the patient's perspective about the perceived

benefits of narratives. The finding can inform those creating stories that can be used in the future for the healing of psychosocial traumas of patients suffering from cancer.

### **Study's Research Questions**

The current study poses the following research questions:

1. What do cancer narratives convey about patients' experience of cancer?
2. What differences emerge in the narrative elements of the narratives patients report "worthy" of sharing and those not worthy of sharing?
3. What are the reasons patients provide for identifying certain narratives as worthy or not worthy of sharing?
4. What do cancer patients want to read in a story about cancer?
5. What do patients report as the benefits of narrative sharing/writing?
6. What do patients report as the benefits of narrative listening/reading?

### **Overview of Methods**

To answer these questions, I analyzed data collected through mailed questionnaires returned by 21 cancer patients who were within two years of cancer diagnosis. The questionnaire began in an open-ended exploratory fashion by asking patients to share a memorable cancer narrative that they would share with others. They then had an opportunity to share a narrative they would not want to share with others. After sharing the narrative, the patient had a chance to give reasons as to why he or she considered that narrative worthy of sharing or not sharing and what they wanted to read in a story about cancer. The patients also had an opportunity to report if the narrative made any difference in their own experience of cancer. The collected data were

transcribed verbatim and analyzed.

Using a qualitative inductive approach, I conducted a thematic analysis of the collected patient narratives. I consider this method to be best suited for this study because the questions this study poses are mainly descriptive in nature. This analytical approach emphasizes inductive development and refinement of descriptive categories that ultimately form to create a coherent description and explanation of the phenomenon (Charmaz, 2000). A hypothesis-driven approach is not warranted for this study because of the nature of the questions specifically posed. The qualitative approach allowed for an exploratory investigation of the detailed narrative accounts provided by the participants.

### **Conceptual Framework**

Research on illness narratives suggests that the content of narratives yields understanding of the illness experience. Sandelowski (1991) argues that for the study of illness narratives, studying content is important in order to illuminate experience. Reisman (1993) also describes the importance of asking questions such as, what constitutes a story and how might various stories be compared? As described above, this study in its broadest sense utilizes inductive development and refinement of descriptive categories (Charmaz, 2000). These categories will ultimately aid to create a coherent description and explanation of the content and experiences described in the cancer narratives used in this study.

The social sciences, as well as literary and linguistic sciences, have realized the importance of studying narratives in depth. Franzosi (2010) describes that scholars have shifted their focus from macrostructural characteristics of text such as genre, sequence and plot to microlevel structures such as the types of characters/actors and verbs found in

narrative texts. All these elements comprise narrative structure. Since this study mainly asks questions related to the experiences and of the individuals, it is restricted to analyzing the content of the narratives. This study will refrain from an analysis of the structure of the narratives.

The study will employ a thematic analysis of the data using a narrative approach to answer the research questions. The researcher immerses himself in the data to allow new insights to emerge from it (Kondracki & Wellman, 2002). The thematic analysis involves identifying important content in the data which is related to the research questions (Boyatzis, 1998). The analysis progresses from identifying meaningful units of data to establish more inclusive categories (Creswell, 2009). Finally, the analysis of the findings is presented, providing illustrative narrative excerpts and participant responses (Reissman, 2008).

## **Chapter 2**

### **Literature Review**

#### **Introduction**

The discussion begins with an overview of illness narrative research and while the aim of this literature review is to establish the importance of this study, it also provides a benchmark for comparing the results from this study with other findings (Creswell, 2009). This literature review is not an exhaustive description of illness narrative research. Rather, this review examines representative published scholarly research in the areas related to aims of this study.

#### **Literature Selection**

To identify literature on illness narratives, I conducted an online search using electronic databases via the Pennsylvania State University Libraries website. The search comprised the social science, social science and medicine, medicine and nursing literature. I used the Medline (from 1966), Embase (from 1988), PsychINFO (from 1967), CINHALL (from 1982) and Communication Mass Media Complete (from 1920) online databases. I used the following search terms for gathering the research articles and books: cancer narratives, health narratives, illness narratives, narrative and medicine, patient narratives, narrative analysis, narratives and healing. The search results were restricted to papers published in English or translated into English. After procuring the literature, the literature was read for relevance to this study. Only the research relating to illness narratives and cancer narratives was retained and studied in depth. The following is an overview of research that informed and guided the current study, describing

research on illness/cancer narratives, elucidating existing gaps in this research, and positioning this current study to address those gaps.

### **The Re-Emergence of Illness Narratives**

The purpose of this section is to place this study within the background of illness narrative research. This section also describes reasons as to why there is a considerable emerging interest in the study of narratives in health related settings (Bury, 2001).

The 20th century gave rise to the biomedical models of medicine which contend that disease results from cellular abnormalities (Wade & Halligan, 2004). This led to the notion that disease is situated in cellular pathology and soon became the dominant medical paradigm. This in turn led to the development of a medical profession which had rigid boundaries and exerted almost complete authority over illness and its treatment (Lawrence, 1994). These developments in the medical professions inadvertently led to the disregard of the patient experience of illness and the patient's life circumstances. Sociologist Jewson (1976) noted that the rise of scientific bio-medicine led to a diminished importance of the patient's experience, ignoring the wealth of information provided by the patient's illness narrative. During this paradigm shift, taking a patient's history was reduced to eliciting information about the objective signs and symptoms of the disease rather than listening to his or her experience of that disease. This can be understood in the following quote:

“The task of the doctor, increasingly in the 19th century and into the 20th, was to translate these pieces of information into a definitive diagnosis that linked the disease to specific biological causes and outcomes, rather than to the patient's circumstances or lifestyle, let alone to their beliefs or values” (Bury, 2001, p.

266).

Although the bio-medical model has overshadowed the patient's experience during the past century, many factors have brought patient narratives back into focus for the social sciences and medicine in recent years. Two major changes have been attributed to the reemergence of illness narratives (Bury, 2001). Firstly, in the industrialized world, there has been a relative decline in the importance of the infectious disease, which is the foundation of the bio-medical model (Bury, 2001). The second more important factor is the growing impact of degenerative and chronic illnesses (Strauss 1975; Bury 1991). An aging society has given way to the predominance of chronic physical and psychosomatic illnesses. Thus, long term management and care has superseded treatment and cure (Gerhardt, 1989). Chronic illnesses, such as cancer manifest themselves in diverse array of symptoms and patient experiences; therefore, the subjective patient view needs to become audible once more (Bury, 1998). The medical profession is also having increasing debates about the value of 'holistic medicine' and of listening to the patient, which began in Britain in the 1950s by individuals such as Balint (1955) and has been furthered by Dossey (1991) and Chopra (1989).

Most recently, illness narratives, and the links with 'history taking' in medicine, have themselves been associated with moves to improve care that do not rely entirely on what may be regarded as a narrow view of scientific medicine or its 'evidence based' practice and evaluation (Greenhalgh & Hurwitz 1999). Social science as well as medical science has much to gain from narrative medicine. Rita Charon a physician and narrative scholar is a significant proponent of the discipline of narrative medicine. She describes that a scientifically competent medicine is not enough to help patients handle disease and



cope with illness and dying. “Along with their growing scientific expertise, doctors need the expertise to listen to their patients, to understand as best they can the ordeals of illness and to honor the meanings of their patients narratives of illness” (Charon, 2006, p.3).

Some studies of illness narratives were based on the idea that illness inadvertently caused the disruption or discontinuity in an individual’s life (Bury, 1982). The illness was thus considered to block the flow of daily life and the individual afflicted by the illness was required to alter the grounds on which they planned and assessed their lives (Charmaz 1992). Acute illness was thought to be of only a temporary significance and constituted a brief and restricted disruption which incited individuals to realize the fragility of their lives (Hyden, 1997). However, within the context of chronic illness, the study of illness narrative became particularly interesting since chronic illness caused prolonged disruption of individual’s lives and inevitably led individuals to reconfigure their identities (Corbin & Strauss, 1987). Narratives thus offered a chance to tie together the broken ends of time caused by the chronic illness and therefore create a new perspective and “to fit the illness disruption into a temporal framework” (Hyden, 1997, pp.53).

The illness event can be understood as a life process through narrative, which has the ability to relate the illness event as well as other life events in a temporal context (Ricoeur, 1984). This idea of life disruption due to chronic illness and reconnection of the patient’s life through narrative led to sociological accounts of chronic disease which emphasized the variations in the illness experience and the cognitive and emotional resources that patients employed to cope with the disease (Bury, 1982; Mathieson & Stam, 1995). Sociological studies proposed a typology of illness narratives such as

Frank's (1995) 'restitution', 'chaos' or 'quest' plots in illness narratives and Robinson's (1990) 'stable', 'progressive' and 'regressive' life trajectories. These initial studies demonstrated the evidence for undertaking serious studies of illness narratives.

Subsequently the study of narratives has been approached from a wide variety of disciplines using different methodological and theoretical approaches (Reissmann, 2008).

Structure and content of illness narratives has been studied by to understand the plot, characters, sequencing components of the illness narratives (Davis, 1998). Narrative messages have also shown the ability to depict various features of the illness experience (Van Der Molen, 1999; 2000). In the aforementioned research the actual narrative is the data of interest to the researcher. Subsequently narrative messages have shown to be effective in transmitting health information (Harper-Chelf, 2000) and have been posited to be important vehicles of health behavior change (Kreuter et al., 2007). The knowledge, attitudes, beliefs and behaviors are the variables of interest in narrative and public health communication research. Researchers have demonstrated that narratives have therapeutic benefits when individuals listen to narratives (Sunwolf & Frey, 2005) as well as when individuals write narratives (Pennebaker & Seagal, 1999). In therapeutic narrative research the effect of the narrative on the individual is of interest rather than the narrative itself. This study aims to explore the illness experience of cancer as well as tries to understand the role that narratives play in it. The study uses the background of previous illness narrative and cancer narrative research to make a case for its research questions.

### **Illness Narratives and the Patient Experience of Cancer**

As discussed above, there is a general consensus that chronic illness inevitably needs the afflicted individuals to deal with a variety of issues ranging from emotional and

existential to dealing with the complexities associated with medical care. This has led to a number of studies attempting to understanding the experience of illness. A review of illness experience research has indicated that in general individuals have a subjective way of experiencing their illness and they give meaning to their experience of illness through the metaphors, cognitive representations, and images which they create after learning about their condition (Pierret, 2003). Narratives are an appropriate means of studying issues of health, healing and chronic illness because they capture the complexities that medical patients are faced with (Harter, Japp, & Beck, 2005). Thus, the exploration of the narratives of patients with a chronic illness may throw light on the nature of the disrupted experience, its meanings and the actions that are taken to deal with it (Bury, 2001). The different ways in which the cancer experience can be expressed in narratives (e.g., third person story, metaphor, illness narrative) offers the possibility for many strategies to communicate experiences (Kreuter et al., 2007).

Narrative research on the illness experience of cancer suggests that medically related information is an important component of the cancer experience for patients (Salander, 2002; Van Der Molen, 2000). Cancer patients indicated that experiences of diagnosis created a lot of anxiety and that they preferred receiving straightforward and honest information about their diagnosis (Salander, 2002). Also cancer patients found it hard to process medical information soon after diagnosis and were also less likely to articulate their information needs (Van Der Molen, 2000). Treatment related information was sought after by cancer patients (Van Der Molen, 2000) and it patients reported that clear information about treatment helped the patients feel less burdened with the cancer diagnosis (Salander, 2002).

The cancer experience has known to bring up a host of psychosocial factors for patients. Narrative studies of cancer experiences have shown themes that indicate that the cancer experience highlighted the importance of God, family and social support for patients (Overcash, 2004). Cancer patients have indicated in their narratives that their spiritual faith and belief in God gave them the strength to deal with cancer (Overcash, 2004). Equally important have been the references to social support. Cancer patients have indicated that social support is “extremely important” (pp.51) part of their cancer experience and actively sought out social support (Van Der Molen, 2000). Maintaining a positive attitude throughout the cancer experience was also considered to be an important component in “beating breast cancer” (Overcash, 2004, pp.1157). Metaphors have been important way of conceptualizing the cancer experience in narratives (Tuecher, 2000). Metaphors help individuals structure abstract, emotional, or other experiences that are not clearly delineated (Lakoff & Johnson, 1980). The literature regarding metaphors also suggests that metaphor along with providing the intellectual and linguistic tools for communication is also a method of coping with illness (Guinjoan & Ross, 1999; Jenny & Logan, 1996; Mallinson, Kielhoftner, & Mattingly, 1996). The cancer metaphors literature suggests that “for physicians and patients alike, war is a dominant metaphor” (Reisfield & Wilson, 2004, p.4024). War related metaphors are described to be masculine, power-based, paternalistic and violent (Reisfield & Wilson, 2004). Also an assumption with the use of war-related metaphors is that in case the treatment is unsuccessful, the patients failed the treatment as they could not “fight” strongly enough rather than the treatment failing the patients (Reisfield & Wilson, 2004). It is also important to balance the instinct to fight with words of healing and acceptance (Penson et

al., 2005). Thus it is important to study the different varieties of metaphors that individuals use to describe their cancer experience to illuminate differently possibilities for metaphorical conception of the cancer experience.

The current system of medicine is thus missing out from learning about what constitutes the illness experience for cancer patients (Greenhalgh & Hurwitz, 1999). One of the earlier studies of chronic illness experience suggested that medicine was paradoxical “cultural system, as both an important resource to people in times of distress and pain and as a constraint in their search for the deeper meaning of experience” (Bury, 1982, p.18). Medicine still needs to work hard to incorporate narratives into patient care (Charon, 2006). Patients understand their illness in narrative ways and if physicians disregard narratives health care will inevitably be at a loss (Coulehan, 2003). Physicians can better understand patient perspectives and have the opportunity to vicariously experience the patient’s world (Hawkins, 1999). Therefore an in-depth study of cancer narratives for studying the patient experience of cancer is justified.

Previous research on cancer narratives suggests that studying narrative content gives a rich understanding of the patient experience of cancer (Frank, 1995; Reissman, 2008). Since cancer is known to create contradictory feelings and thoughts amongst patients such as fostering feelings of hope and despair; acceptance and denial at the same time, narratives have the ability to capture this complexity (Carlick & Biley, 2004; Ezzy, 2000). In fact, during the process of forming narratives, distinct aspects of the individual experience are highlighted and previous life experiences are used to help create meaning and understanding (Baktin, 1981; Vezeau, 1994). However, there has been limited research on the study of narratives which are specific to cancer (Kreuter et al., 2007).

Learning what constitutes the illness experience is crucial for both health care practitioners and communication scholars. The patient experience of cancer can give us a good understanding of psychosocial factors for cancer patients. The impact of psychosocial factors on cancer health outcomes is a current discussion in health care. The impact of psychological factors influencing survival from cancer, particularly breast cancer has gained a certain degree of popularity (Reynolds et al., 2000). Research has shown that when patients approach illness with positive attitudes such as maintaining a “fighting spirit” during treatment, it has a positive impact on cancer survival rate (Greer, Morris, Pettingale, & Haybittle, 1990). These findings suggest that we should include psychosocial interventions to encourage cancer patients to frame a positive attitude towards treatment.

There are, however, opposing viewpoints about the influence of positive psychosocial coping and cancer health outcomes. A systematic literature review of the impact of psychological coping on cancer health outcomes concluded that there is “little consistent evidence that psychological coping styles play an important part in survival from or recurrence of cancer. People with cancer should not feel pressured into adopting particular coping styles to improve survival or reduce the risk of recurrence” (Petticrew, Bell & Hunter, 2002, pp1). Therefore there lie opposing viewpoints about the impact of positive coping strategies on cancer. A possible reason for the opposing viewpoints could be because research on impact of psychosocial adaptation on health outcomes does not address the patient’s perspective in an open ended fashion. It does not explore if cancer patients independently experience the need to have positive attitudes. It also does not explore if and in what ways do cancer patients report how their attitudes or coping

strategies affect their cancer experience. Inductive studies of the cancer experience are warranted to study if patients report how their attitudes or coping strategies benefited them. Research into the cancer experience will also demonstrate if patients felt forced to adopt a certain coping style. All the above cited research warrants an in-depth investigation of the cancer experience and narratives are a suitable method for obtaining the cancer experience from cancer patients. I therefore pose the first research question for this study.

RQ1: What do cancer narratives convey about patients' experience of cancer?

### **Narratives and Coping with Cancer**

Along with studying what constitutes the patient experience of cancer, it is also important to know how patients deal with cancer. The cancer experience has been known to force people to undergo changes in their life, deal with a lot of uncertainty and learn how to navigate the health care system (Nail, 2001). The numerous physiological and psychosocial stresses related to cancer create a need in patients to learn how to cope with these stresses (Halstead & Fernsler, 1994; Johnson, 2000). Coping refers to the “cognitive and behavioral efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship” (Folkman & Lazarus, 1985, p.152). The process of coping also involves what is described as primary and secondary cognitive appraisal (Lazarus & Folkman, 1984). Cognitive appraisal is a process wherein an individual evaluates or categorizes the significance of an interaction with his/her external or internal environment. In the primary appraisal process the individual assesses whether the encounter with the environment presents a threat to him/her. If the interaction with the environment is evaluated as a threat, then the individual determines if anything can be

done about this threat in the secondary appraisal. It is during the secondary appraisal process, if the individual chooses to deal with the threat then he/she selects the option of coping. Subsequently, in a general sense coping has been identified to be either problem focused or emotion focused in.

Problem focused coping entails attempting to do something constructive in order to alter the stressful situation (Folkman & Lazarus, 1988). The second type is emotion focused coping wherein the focus is on the regulation of distressing emotions so that the stressful situation is more manageable (Folkman & Lazarus, 1988). Further research in the two types of coping has revealed different strategies of coping that individual's use; these coping strategies are sometimes referred to as coping styles. Problem focused coping showed conceptually distinct aspects in terms of active coping, planning, suppression of competing activities, restraint coping and seeking of instrumental social support (Carver, Scheier & Weintraub, 1989). The aspects of emotion focused coping showed that seeking of emotional social support, positive reinterpretation, acceptance, denial, and turning to religion were the coping strategies used (Carver et al., 1989). However, individuals can use more than one strategy at a time. In fact research suggests that individuals choose multiple coping methods depending on the situation and most individuals use more than one method simultaneously in a dynamic fashion (Dunkel-schetter et al., 1992; Folkman 1997; Taylor, 2000; Morgan, 2001). Narratives could also be a possible coping method for cancer patients.

The human experience of suffering, loss and recovery can be told powerfully in the form of a story which can serve to benefit and inspire the narrator of the story as well as the audience (Radley, 1999). As discussed previously, narratives give people the ability



to deal with life interruption due to disease and therefore can serve as a way to cope with disease. When patients place events in a sequence while eliciting a narrative it helps restore a sense of order to the patient's life (Heiney, 1995; Hyden, 1997). Carlick and Biley's (2004) proposed theory posits that as a medium, narratives have the potential to enable people to cope with cancer. The possible explanation of the coping function of narratives can be related to their ability to transmit knowledge and information (Harper-Chelf et al., 2000), articulate and express emotions (Pennebaker & Seagal, 1999) and create a sense of social support (Kreuter et al., 2007). Also certain narrative elements may be highlighted to help in the coping process.

Illness narratives that review the individual's life generally highlight relationships, achievements and human values of the individual thus helping to enhance the worthiness of the individual which has been destroyed by the disease (Chochinov, 2002). In some narratives, individuals may depict themselves as brave characters that try new approaches and use dramatic metaphors to illustrate their fight against their illness (Frank, 1995; Ezzy, 2000). Thus narrative may lend itself as an important approach to coping with cancer. An overarching aim of this study is to explore the role that narratives play in the experience of cancer and therefore also see if narratives help in coping with cancer.

**Cancer narratives and information.** Research has demonstrated that stories have the ability to transmit knowledge and are therefore are an appropriate way for patients to seek information (Harper Chelf et al., 2000). The process of storytelling creates a learning environment wherein individuals find it easy to share knowledge, seek information and make decisions (Banks-Wallace, 1998). Narratives can "facilitate

attention, comprehension, and recall of cancer related information,” (Kreuter et al., 2007, p.225). Heliker (1999) showed that the healing stories offered the participants the opportunity to explore choices and possibilities within a non-judgmental relationship. The above stated narrative functions can thus be understood as problem-focused coping strategies which involve objective information seeking and decision making (Lazarus & Folkman 1984). Thus, narratives may serve as a tool for problem focused coping for cancer patients.

Illness narratives can also serve to function as a tool to articulating emotions such as hope, fear, and anxieties which are so common to a grievous sickness such as cancer (Hawkins, 1999). Of all emotions that are relevant in the cancer experience, hope has been found to be of significant importance for cancer patients. Individuals diagnosed with cancer have identified hope as one of the most essential components in their life after their cancer diagnosis (Chi, 2007). The need for hope is irrespective of the stage of cancer. Most cancer patients report wanting to find hope or help increase their hope regardless of their cancer stage (Chi, 2007). The level of hope and level of coping have shown significant relationships (Felder, 2004). In fact hope and coping with cancer have described as intertwined in way that “hope can be viewed as antecedent, a strategy or the outcome of coping” (Felder, 2004, pp.321). Even in individuals with advanced stages of cancer the level of hope has been reportedly high, and hope was related to coping with cancer independent of gender, age, marital status, education, or site of malignancy (Felder, 2004). Hope has even more of a distinct impact on the American discourse about cancer (Delvecchio Good, Good, Schaffer & Lind, 1990).

Within American ideas of mind and body there is a deeply felt cultural conviction

that that “individualized will can influence bodily processes” (Delvecchio Good et al., 1990, p.75). Also, this distinctive American conceptualization of hope has had a significant role in shaping medical research, medical practice standards and as well as influenced attempts to provide humane and beneficial care to cancer patients (Delvecchio et al., 1990). After attending a cancer-related storytelling workshop, a survey of persons with a diagnosis of cancer, their caregivers, and members of the general public (n = 94), found that 97% of the respondents reported storytelling was a helpful way to coping mechanism with cancer (Harper-Chelf, 2000). Also 85% of the survey respondents reported they felt hopeful after they heard other people’s stories of living with cancer (Harper-Chelf, 2000). This indicates that narratives may help individuals cope with cancer by instilling hope in them. A possible way in which the cancer patients experience hope from narratives is through the information conveyed in the narratives. In a narrative study of one patients experience with the diagnosis of cancer, a major theme that that emerged was the importance of medical information as shaping the experience of cancer (Van der Molen, 2000). Thus an in-depth study of cancer narrative messages is important to understand how narratives can help how patients deal with a cancer diagnosis.

Health information in narratives can help increase patients’ understanding of cancer diagnosis, treatment, and survivorship as well as gain patient compliance with cancer prevention and control (Kreuter et al., 2007). Narratives are being considered to “serve as guidebooks to the medical experience itself, shaping a reader's expectations about the course of an illness and its treatment” (Hawkins, 1999). Previous research indicates that cancer patients frequently requested information regarding the medical aspects of their illness (Van Der Molen, 2000). Thus with their easy readability and use

of colloquial language, narratives could be tools for communication of cancer information as well as persuade individuals towards health behaviors (Kreuter et al.) Research on the persuasive effects of narrative messages finds narrative to be more persuasive as compared to statistical messages, “even when relevant statistical information is made readily available to subjects,” (Bordgida & Nisbett, 1977, p.24). Narratives can be constructed to communicate cancer prevention, screening and treatment related information. An experimental study used to promote colorectal cancer screening found that participants who read narrative messages about cancer screening reported that barriers to message screening would have less of an impact on future screening experience (Dillard, Fagerlin, Cin, Zikmund-Fisher & Ubel, 2010).

Taking a narrative approach to convey health information can be especially helpful in the context of cancer because the morbidity and mortality are highly dependent on preventive and screening measures that individuals take for cancer prevention or early detection and treatment. Individuals living with cancer reported that they found positive stories about other individuals suffering from cancer were more helpful than negative (Taylor, Aspinwall, Giuliano, Dakof, & Reardon, 1993). However, no prior research has asked patient’s to self report narratives they would like to share and narratives they would not like to share. The narratives obtained from the patients themselves will yield important information about the content of narratives that patients want to hear. Also we can know the differences in the narratives that patients would like to share as opposed to the narratives they would not like to share. Conclusions can thus be made about the basis on which patients decide the worthiness of narratives. Therefore, a comparative study of the narratives would provide a substantial contribution to understanding what cancer

patients find appealing and worthy of sharing and what cancer patients disapprove of sharing in cancer stories. This study therefore argues for a comparative analysis of the narratives that individuals list as worthy of sharing or not sharing. This leads me to the second research questions of this study, which is

RQ2. What differences emerge in the narrative elements of the narratives patients report “worthy” of sharing and those not worthy of sharing?

As described above this study aims to investigate the differences between narratives that individuals find worthy and not worthy of sharing, however the narratives “worthiness” is still something that is decided by cancer patients. My analysis of the differences in narratives reported as worthy of sharing or not sharing will inevitably be influenced by my interpretation. I can promise to take an oath to be an objective researcher. I can also choose to take the stance of a researcher who is immersed in the data, who shares a connection with my participants and describes the results in relation to my own clinical experiences. Either of those choices still does not make me an expert in the cancer experience. The only true experts about the cancer experience and the effective narrative messages in that cancer experience are the patients themselves. The cancer patient is the expert because he/she is the only individual who has the lived experience (e.g., as a cancer survivor) of that condition. Cancer patients are not experts because of their professional credentials (e.g., being a physician or nurse or a researcher) but they are experts due to having the first hand experience of cancer (Kreuter et al., 2007). Therefore it is important to investigate on what basis to cancer patients decide if a narrative is worthy of sharing or not sharing. The reasons that cancer patients give for identifying narratives as worthy of sharing or not sharing will give valuable insights to

understanding cancer patient's criteria of narrative worthiness. Therefore, my next research question aims to investigate the patient's responses to the narratives they share in this study.

RQ3. What are the reasons that patients provide for identifying certain narratives as worthy or not worthy of sharing?

Along with learning what makes narratives worthy of sharing, it is also important to learn what exactly patient's expect to read in a cancer narrative. After early failures of linear information campaigns directed to passive audiences (Mendelsohn, 1973), communication experts learned that they needed to know more about their audience's needs along with obtaining reactions to the materials still in the developmental stages (Freimurth & Mettger, 1990). If narrative messages are to be developed for cancer patients, it is important to ask them what they want to read in it. Early formative research was described as not actually involving the audience, rather placing them in a reactive and not proactive role; an example was that most pretesting audiences were asked for their feedback on the message concepts and strategies rather than being invited to help formulate the ideas (Freimurth & Mettger, 1990). Thus we need more formative research techniques using open ended questions in which members of the audience can frame their own responses rather than close-ended questions in which the researcher defines the range of answers (Freimurth & Mettger, 1990). There is lack of research about narrative content from the cancer patient's perspective. Therefore, to actually learn what needs to be present in a cancer narrative we must value the opinions of the experts, i.e. the cancer patients themselves. Thus along with their responses about the cancer narratives that the patient share, it is necessary to ask them in an open ended fashion, what do they want to

read in a story about cancer. The results yielded from this study can thus be used as formative research to understand the important elements or components of narratives that cancer patients want to read in a cancer narrative. I thus state my fourth research question as:

RQ4. What do cancer patients want to read in a story about cancer?

### **Health Benefits of Story-telling and Story-listening**

The study of narratives from a therapeutic standpoint has revealed that listening or reading narratives as well as sharing or writing narratives has health benefits for individuals. There has been substantial evidence generated to suggest that the “formation of a narrative is critical and is an indicator of good mental and physical health” (Pennebaker & Seagal, 1999, pp.1243). Writing narratives about traumatic experiences has shown to provide long term improvements in the mood and happiness for individuals (Pennebaker, 1997). Studies of narrative writing have also revealed that narrative writing can improve the immunological profile of the individual (Pennebaker, Glaser & Kiecolt-Glaser, 1988). Writing about traumatic experiences had positive effects on the immune activity of T-lymphocytes (Pennebaker, Kiecolt-Glaser, & Glaser, 1988). Similarly another study found that individuals having latent Epstein-Barr virus infection who wrote or verbally expressed themselves about traumatic or stressful events had lower anti-body titers, suggesting better cellular immune control of the virus (Esterling, Antoni, Fletcher, Margulies, & Schneiderman, 1994). An emotional writing intervention for HIV positive individuals revealed improved immune response indicated by an increased CD4+ T lymphocyte of the participants (Petrie et al., 2004). Psychosocial trauma and stress has been proven to impact the cellular immune response, including natural killer (NK) cell

function and modulation of apoptosis, i.e. programmed cell death (Kiecolt-Glaser, Robles, Hefner, Loving & Glaser, 2002). Psychosocial factors are now being implicated in the immune function of individuals diagnosed with cancer. Psychosocial stress and its impact on the immune system have been implicated to “ultimately affect the occurrence and progression of certain tumors” (Kiecolt-Glaser et al., 2002, pp.165). Narratives may therefore provide a possible tool for individuals to deal with the psychosocial stress of cancer.

A possible explanation for the health benefits of narrative writing is that writing aids individuals to express themselves. Catharsis theory (Scheff, 1979) suggests that in order to receive the health benefits of emotional disclosure, "verbal recall is neither necessary nor sufficient for therapy, and emotional discharge is both necessary and sufficient" (p. 77). Research on the venting of emotions also suggests that health benefits for emotional expression are present only when individuals cognitively process their emotional experiences (Lewis & Bucher, 1992). Narratives are a unique form of self-expression in the sense that they implicitly require individuals to cognitively process their experiences. Therefore, health benefits of narratives are available to individuals when they express their emotional experiences through language (Pennebaker & Seagal, 1999).

Another possible way in which narratives provide health benefits could be related to their function of making sense of life events (Hyden, 1997). The sense-making function of narratives provides individuals with the structure and meaning to deal with emotional experiences. Clark's (1998) investigation of childhood imaginative narratives in the face of chronic illness gives us a glimpse of how constructing narratives can help cope with even with emergency medical situations. In Clark's (1998) interviews with



asthmatic children, the fear of death was a universal concern and the lack of breath always carried a sense of life-threatening consequences. Clark (1998) reported that one child had sheets on his bed depicting the Teenage Mutant Ninja Turtles. This provided a basis for the child's imaginative narrative, in which, if a nighttime emergency with his breathing occurred, one of the Turtles would fly off the sheets and go to get the doctor. The child reported that this calmed him during the asthmatic attacks. Through the imagery described by the asthmatic child in Clark's (1998) study, we can conclude that narratives serve as a means of working through individual's emotions and suffering brought on by a life-threatening illness (Sunwolf & Frey, 2001).

Once individuals give their emotional experiences structure and meaning by constructing narratives, the emotional effects of that experience become more manageable for the individual (Pennebaker & Seagal, 1999). Writing about the traumatic experience can help the individual then be somewhat complete with that event and consider the event as part of the life experience (Hyden, 1997). The diagnosis of cancer can definitely be considered as a traumatic experience for individuals. Thus the study of the possible benefits from writing or sharing narratives for individuals diagnosed with cancer is warranted. A study of these benefits from the perspective of the individual diagnosed with cancer is also important. The following research question will address the perceived benefits of narrative sharing or writing.

RQ 5: What do patients report as the benefits of narrative sharing/writing?

Listening to narratives has also shown benefits in terms of health and health behavior. Considerable amount of research on the benefits of listening to stories has been conducted in the context of listening to fairy tales or folk narratives. Narration of

folktales to children with eating disorders has demonstrated improvement in health behavior and children's relationship with food (Anderson 1993, 2004; Hill, 1992). The narrated fairy tales served as way to understand and accommodate the desirable features of the tales characters for children, thereby creating a model for good eating behavior (Hill, 1992). Interpretive folk tales have helped women face issues of gender during midlife and older age (Thomas, 1997). Listening to fairy tales has also helped individuals cope with chronic headaches (Rueveni, 1995). In the context of end of life care, listening to life stories yielded decreased anxiety towards death in elderly individuals (Stone, 1996).

In comparison to the research on benefits of folk narratives, considerably less research has been done to determine the benefits of listening or reading narratives of individuals undergoing similar stressful events. The coping benefits of listening stories about others undergoing stressful events revealed that reading stories of similar others had benefits for individuals who were currently in stress (Taylor, Aspinwall, Giuliano, Dakof, & Reardon, 1993). Individuals living with cancer reported that they found positive stories about other individuals suffering from cancer were more helpful than negative (Taylor et al., 1993). An experimental study on college students in regards to college adjustment revealed that negative stories of college adjustment made students feel lucky by comparison, whereas positive stories offered students a better role model as well as a sense of hope (Taylor et al., 1993). Thus perceived helpfulness of the narratives was dependent on type of story that the student was presented with. Therefore stories that have a positive connotation and foster a sense of hope are more like to be considered as worthy of sharing.

There is empirical evidence to suggest that social support has physical as well as psychological benefits (Broadhead et al., 1983). Thus, certain types of illness narratives from individuals suffering from “similar illness may have the most profound healing and comforting effects for people with newly diagnosed illnesses” (Sunwolf & Frey, 2005, p. 249) through a possible pseudo relationship with the characters in the narrative (Kreuter et al., 2007). Narratives are a suitable means through which individuals can address the existential and psycho-spiritual aspects that are part of life threatening diseases such as cancer (Lin & Bauer-Wu, 2003). Research suggests that cancer can actually deepen one’s relationships, increase self esteem and help individuals find purpose and meaning in life (Lin & Bauer-Wu, 2003) “in spite and because of suffering” (Kreuter et al., 2007, pp.228). Reading or listening to illness narratives may help individuals address these meaningful life issues for themselves.

The mechanism for benefits of listening to narratives has been attributed to the induction of a trance like mental state that yields potential healing effects. The words which generally appear in the beginning of a fairy tale, "Once upon a time . . ." can induce a soothing, familiar light trance and the idea of "holding an audience spellbound," is often used to describe an audience's altered state of listening to a well narrated story (Sunwolf & Frey, 2005) A psychotherapist storyteller has described such trances as an inner-directed state of consciousness; which means that though the listeners' eyes may be seeing the story-teller, their consciousness is turned inward (Martin, 1993). These explanations, however, may work better in situations where individuals do not personally relate to narratives such as in the case of fairy tales or folk narratives. Listening to narratives may serve the function of creating connections between individuals. In a

narrative intervention for encouraging Alaskan Native American women to get Pap tests for cervical cancer (Strickland, Chrisman, Yallup, Powell, & Squeoch, 1996), researchers gained access to the story circles of Native American women. The elders in the Native American women had the greatest influence on younger women starting their journey of womanhood (Strickland et al., 1996). Consequently the researchers proposed that the process of getting a Pap test needs to be retold by the Native American elders as an important part of becoming a woman in their story telling groups (Strickland et al., 1996). This suggestion indicates that the younger women can relate to the Pap test more since it is easy for them to connect with the narrators of the story. Thus, narratives through this relating function may act as means of connecting people (Sunwolf & Frey, 2005). Even if the individual does not know whose story they are listening too, narratives may still provide perceived social connections. Individuals are known to feel a connection and sense of involvement with the characters portrayed in popular media (Rubin & Perse, 1987) as well literary figures in history (Caughey, 1984). These connections have been referred to as parasocial interactions and have shown similar attributes to ordinary social interactions (Giles, 2002). Illness narratives may thus serve the function of social support for disease afflicted individuals through parasocial interactions (Kreuter et al., 2007). Research is thus warranted to investigate if individuals diagnosed with an illness such as cancer actually perceive benefits of listening to or reading narratives.

The research related to healing effects of narratives deals has been concerned with the effects that narratives have on individuals rather than what people describe as the healing effects of narrative listening or reading. Also more research is needed to understand how individuals who have been diagnosed with a serious illness such as

cancer react to the narratives of individuals with a similar diagnosis. Thus the knowledge of what patients describe as beneficial effects of cancer narrative listening or reading is crucial if they are to be reproduced for public health care interventions using narratives.

This leads me to the final research questions of this study, which is:

RQ 6: What do patients report as the benefits of narrative listening/reading?

## **Chapter 3**

### **Methods**

#### **Introduction**

The overarching aim of this study is to provide an in-depth understanding of the role that narratives play in the experience of cancer. I will identify commonalities and differences that emerge in the narratives that patients would share and those they would not want to be shared, as well as the participants' responses to the open-ended questions. I will aim to give a descriptive understanding of results that emerge pertinent to the research questions. I will in addition describe my thoughts and perceptions about the results from my own standpoint of someone experienced in the science of medicine and healing.

In this section, I describe the qualitative analytical approach I have chosen in this study. I also describe the methodology chosen for this study as well as the specific methods used to answer each of the research questions. I also describe the strategy for recruiting participants for this study, along with their characteristics. I will elucidate how the study was conducted and describe where the data will come from for each of the research questions. Strategies for data analysis will also be described in this chapter. I will conclude with the issues related to validity, limitations and ethical issues pertaining to this study.

#### **Research Questions**

The current study poses the following research questions:

1. What do cancer narratives convey about patients' experience of cancer?

2. What differences emerge in the narrative elements of the narratives patients report “worthy” of sharing and those not worthy of sharing?
3. What are the reasons patients provide for identifying certain narratives as worthy or not worthy of sharing?
4. What do cancer patients want to read in a story about cancer?
5. What do patients report as the benefits of narrative sharing/writing?
6. What do patients report as the benefits of narrative listening/reading?

## **Methodology**

**Sampling.** The objective of this study is to achieve a descriptive understanding of the role that narratives play in the cancer experience and not to generalize its findings to larger populations. Keeping this goal in mind, probability sampling is not the ideal choice for this study. Purposeful sampling was used for this study (Maxwell, 2005). Purposeful sampling is a strategy wherein “particular settings, persons, or activities are selected deliberately” (p.88) in order to obtain information that is not available as well from other choices (Maxwell, 2005). The participants chosen for this study can also be described as *a panel*, which refers to “people who are uniquely able to be informative because they are expert in an area or were privileged witnesses to an event” (Weiss, 1994, p.17). In reference to this study, I consider the cancer patients as experts on their disease experience and life circumstances. I refrain from considering them as privileged witnesses due to the grievousness of their condition. However, they definitely have a firsthand account of their condition and disease experience. The initial inclusion criteria for the participants were a minimum of 18 years of age and diagnosed with colorectal

cancer in the past two years. Due to inadequate recruitment in the first six months after the study was launched, the inclusion criteria was then broadened to patients over the age of 18 and diagnosed with any type of cancer in the last two years.

**Participants.** The sample for this study ( $N = 21$ ) includes 19 females and two males. Age of the participants ranges from 21 to 76 years ( $M = 51.9$ ;  $SD = 13.33$ ). The ethnicity of the sample is all white/non-Hispanic ( $N = 21$ ; 100%). Overall the participants had a high level of education, with 13 (61.9%) participants having a postgraduate/professional degree, five (23.8%) were college graduates and three (14.3%) had some college or vocational program. In relation to religious affiliation, 12 (57.1 %) participants reported themselves as affiliated with Christianity, four (19.0 %) participants reported themselves as affiliated with Judaism and the remaining five (23.8%) participants reported no religious affiliation. In regards to the type of cancer, there was a majority of breast cancer patients ( $n = 9$ ; 42.9%). Lymphomas were the next common cancer with two (9.5%) participants reporting Hodgkins lymphoma and two participants (9.5%) reporting Non-Hodgkin's lymphoma. There was one (4.8%) participant each that reported one of the following cancers: bladder, brain, endometrial, GI cancer in ovary, thymoma, prostate, skin and parathyroid.

**Recruitment.** The initial participant recruitment strategy was through flyers posted in Lancaster county church community bulletin boards, church mailboxes or flyers inserted in church weekly bulletins announcing the study for newly diagnosed colorectal cancer patients diagnosed in the past two years. The research team had previously contacted churches for their willingness to participate in the recruitment process for this study. A total of 30 churches agreed to help with recruitment. The flyer included a brief



description of the study and procedures as well as provided an email address and telephone number to contact the research team for more information and scheduling a phone interview. The flyer stated that phone interviews will be audio-recorded. Six months after the initial recruitment strategy, the inclusion criteria were broadened to include any type of cancer diagnosed in the past two years. Also, in addition to the church based recruitment, the content of the flyer was posted on the University on-line listserv in order to create more possibilities for participant recruitment. Posting on the university listserv ensured that the study featured on the University Faculty and Staff Newswire as well. When potential participants called about the study, the recording asked them to provide their name and telephone number. After this, the participant was contacted by a member of the research team to describe details about the study and to ensure that the participant met the inclusion criteria. The recruitment process yielded a total of 28 participants, of which 21 completed the study.

**Data collection procedures.** Once the participants agreed to participate in the study, the research team asked for their name, telephone number, email and mailing address to send the mail-in questionnaire along with two copies of the informed consent form. Participants were provided a stamped envelope to return their answers and one copy of the signed informed consent form. The package was requested to be returned within two weeks of receipt. A telephone call was placed mid-way through data collection to remind the participants of the study. They were asked if they received the materials and to email or call the research team if they had any questions. A postcard was mailed as a reminder for those participants whose materials were not received in the 2 week time period. The “Cancer Survival Cookbook” (Weihofen & Marino, 1998) was

mailed to participants after receiving the completed questionnaire. This cookbook has 200 recipes to help cancer patients as they go through treatment and was favorably reviewed by the Colon Cancer Alliance. Participants were provided the option to have their story returned to them with the mailed cookbook.

**Data preparation procedures.** The mailed questionnaire began in an open-ended exploratory fashion by asking participants to share a memorable cancer experience story shared with them, which they would *want to* share with other cancer patients and survivors. They were posed with the following question, “Is there a memorable cancer experience story shared with you that you would want to share with other cancer patients and survivors?” Subsequently they were asked to share a memorable cancer experience story shared with them that they would *not* want to share with other cancer patients and survivors, for which they were posed the following question, “Is there a memorable cancer experience story shared with you that you would NOT want to share with other cancer patients and survivors?” After that, participants were instructed to read seven narrative messages selected from the illness narrative literature and provide their emotive, cognitive and behavioral responses to the messages; this data will not be analyzed in this study. After they completed the above mentioned task, the participants were again asked if after reading the narrative messages selected from the illness narrative literature if any another memorable cancer experience story come to mind that they would want to share with other cancer patients and survivors. They were asked the following question, “After reading these stories, does another memorable cancer experience story come to mind that you would want to share with other cancer patients and survivors?” this could include a personal experience story. Subsequently, they were asked if after reading the narrative

messages, if they could recall another memorable cancer experience story that they would *not* want to share with other cancer patients and survivors. They were posed the following question, “After reading these stories, does another memorable cancer experience story come to mind that you would NOT want to share with other cancer patients and survivors?” For both these stories (i.e. to share or not share) the participants could include a personal experience story. Finally they were given an opportunity to share any additional story related to their cancer experience and were asked, “After reading these stories, is there any ADDITIONAL memorable cancer experience story that comes to mind?” They were provided two pages of space to write down these potential additional stories. They also had the option to send a typed copy of their stories. The responses to the above mentioned five open ended question prompts were transcribed and were analyzed to answer the first two research questions.

After each of the first two question prompts, the participants were asked in an open-ended fashion why they would want to share or not want to share the story with other cancer patients and survivors. After they reported the first narrative, they were asked, “Why would you want to share this story with other cancer patients and survivors?” and after reporting the narrative to not share they were asked, “Why would you not want to share this story with other cancer patients and survivors?” The participant responses to these open-ended questions serve as the source of the data for the third research question. Subsequently the participants were also asked in an open-ended fashion the following question, “What do you want to read in a story about cancer?” Their responses to this question were transcribed and analyzed to answer the fourth research question.

The fifth and sixth research question which deals with the benefits of narratives for the participants will utilize data from multiple sources. Data procured for the above four research questions will be analyzed for any implicit or explicit mention of benefits of sharing, writing, listening or reading illness narratives. In addition to this, I analyzed participant responses to two open-ended questions which were posed to them after they reported their initial stories to share and not share. The first question was posed to the participants after reporting their stories to share and not share and asked them, “Did the events in the story change anything in your life? If so, how?” The second question was also asked to the participants after reporting their stories to share and not share and was as follows, “How did this story help you with your own cancer experience?”

**Preparing data for analysis.** From the above mentioned data collection procedures, the data were procured and transcribed to yield 30 pages of single spaced text which comprised data for the entire study. For the purpose of analysis and in order to answer each of the research questions, data were divided into six data sets from this body of original data. Subsequently the data were printed for the purpose of reading and analysis which was done by pencil.

The first data set consisted of data for the all the research questions as described above and was for the purpose of a holistic reading (Thomas-Maclean, 2004) which was the entire 30 pages of single spaced text. For the first research question, all the narratives reported by the participants as well as their responses to the open-ended questions were included in one data set. At this point, it is important to consider how this study defines narrative. The definition of narrative can vary depending on the theoretical basis of the discipline (Reissman, 2008). This study will consider the social linguists’ understanding

of narrative as its primary definition. Social linguists define narrative as a “discrete unit of discourse” which can consider a narrative to be an extended answer by a participant to a single question, which is “topically centered and temporally organized” (Reissman, 2008, p.5). This study also assumes that narratives encompass experience, since narratives are considered to structure perceptual experience and organize memory (Bruner, 1987), as well as include events that individuals select, organize, connect, and evaluate as meaningful when describing their narrative (Reissman, 2008). This study will stay away from the social history and anthropological, as well as the psychological and sociological definitions of narrative that may consider narrative as an entire life story or an extended account of lives created from interviews, observations, and documents (Reissman, 2008). Thus, the narrative data in this study includes the stories reported by participants initially as worthy of sharing and not worthy of sharing as well as stories reported as worthy of sharing and not worthy of sharing in the end. All additional stories reported are also included in this narrative data.

Of the 21 participants, 16 participants provided an initial story to share and 13 participants provided an initial story to not share. In terms of the narratives reported after reading the cancer narratives from the literature, 11 participants reported a last story they would want to share and five participants reported a last story to not share. Finally four participants reported additional stories of which one participant reported three separate additional stories. Thus a total of 51 narratives were obtained from the data. Since only the patient narratives were of interest for the first research question, the participant responses to the open ended questions were excluded in this data set. Thus the original comprehensive data set of 30 pages of single spaced text was reduced to 26 pages of

single-spaced text, which excluded the participant responses.

For the second research question, the narratives in the above data set were partitioned into two separate sections for the purpose of a comparative analysis, excluding any “additional stories” and including only stories that were listed as worthy of sharing and those listed as not worthy of sharing. Thus, the six additional stories were excluded from this data set and yielded a total of 45 narratives in 19 pages of single spaced data. The first section consisted of stories listed as *worthy of sharing* by the participants, the second section listed stories *not worthy of sharing*.

For the third research question, all participant responses as to why they would want to share or not share were included in one data set and yielded four pages of single spaced text. Similarly, for the fourth research question participant responses to what they would want to read in a story about cancer were included in one data set and yielded two pages of single-spaced text. Finally, for the fifth and sixth research questions participant responses to the following two questions, “Did the events in the story change anything in your life? If so, how?” and “How did this story help you with your own cancer experience?”, yielded five pages of single spaced text. In addition to the participant responses to the above described questions, the first data set, which includes the entire data will be reanalyzed for mention of benefits related to the narratives.

### **Data Analysis**

This section describes the methodologies employed by this study to make sense of the data in order to answer the research questions. The analytic approach for this study emphasizes the inductive development and refinement of descriptive categories that will ultimately form to create a coherent description and explanation of the phenomena

(Charmaz, 2000). The study conducted a thematic analysis of the data (which includes narratives as well as participant responses) using a narrative approach to answer the research questions. The details of the analytical approach as well as methodological guidelines obtained from the social scientific literature has been described concisely in this section along with defining relevant terms.

**Narrative approach.** There is no specific prescribed method for analyzing narratives and the methodology can depend on the theoretical and methodological approaches that are commonly employed in a discipline (Davis, 1998). In fact, narrative analysis has been referred to as a “family of methods for interpreting texts that have in common a storied form” (Reissman, 2008, p. 11), rather than a singular methodology. Narrative study traditionally involves documenting narrative accounts which are treated analytically as individual units—cases—with the analysis focusing on examining details such as how and why a particular event is storied (Reissman, 2008). Through this case-centered approach, narrative analysis often generates new categories or concepts that emerge within and across cases, and finally point to theoretical propositions. Among those who conduct narrative analysis, there is also a movement towards a broader commentary about “narratives” as a genre of text, encouraging scholars to think beyond the surface of a text (Reissman, 2008). So based on the research questions posed by a study and relevance to a particular discourse, components and aspects of narrative analysis can be given more prominence than others (Davis, 1998).

Since this study’s research questions all focus on the content of the narratives, description of the content of the narratives and participant responses can be achieved through thematic analysis. According to Reissman (2008), when the focus of the study is

exclusively on the content, a thematic analysis approach can be employed where categories of content emerge within and across cases that eventually reveal patterns of meaning. Thematic analysis informs the research questions of this study by identifying the general patterns present in the data (Reissman, 2008). For the first research questions specifically, the thematic analysis involved generating a codebook and calculating descriptive statistics of the codes. Also for the first research question particular attention was paid to the patient experience as expressed in the narratives. For purpose of clarity, I will first describe the process of thematic analysis of the data as well as the guidelines from social scientific literature for studying experience in narratives. Finally I will describe the hermeneutic approach employed and described in the end of this study.

**Thematic analysis.** Thematic analysis can be described as an investigation by a researcher to find themes that help describe a phenomenon (Daly, Kellehear & Gliksman, 1997), and is a form of “pattern recognition” (p.4) within the data (Fereday & Muir-Cochrane, 2006). A theme can be defined as “a pattern in the information that at minimum describes and organizes the possible observations and at maximum interprets aspects of the phenomenon” (Boyatzis, 1998, p. 161). The thematic analysis process involves connecting important findings discovered in data analysis (Boyatzis, 1998) to describe patterns that cut across the data.

The first step in thematic analysis of the narrative data and participant responses involved entering the text and reading through the text to find categories most pertinent to the research questions (Muller, 1999). This step involved reading and re-reading the narratives and participant responses for the purpose of data reduction. Data were reduced and re-constructed emphasizing inductive category development and refinement. After



the first holistic reading, the data was read in detail to identify important moments (Boyatzis, 1998) or meaningful units of data (Strauss & Corbin, 1998) which seem salient and relevant to the purpose of the research (Baptiste, 2001). Data is organized into “segments of text” (p. 186) before assigning any meaning to the information available (Creswell, 2009). This process has been described as the researcher “zooming in” to identify important underlying ideas in the data (Reissman, 2008). This initial process can be defined as tagging of the data (Baptiste, 2001). Tagging refers to “the process of selecting from an amorphous body of material, bits and pieces that satisfy the researcher’s curiosity, and help support the purpose of the study” (Baptiste, 2001, p.10). After each data unit was tagged, it was compared to previous data units to determine if it represented the same or different meaning. This process is called the constant comparison method (Strauss & Corbin, 1998). The constant comparison ensures that there is no overlap in the tags and they are mutually exclusive at that point. The goal of this open coding process is to identify distinct groups in the data that are defined by a specific set of properties and dimensions (Strauss & Corbin, 1998).

After the data was tagged, the tags having similar characteristics were placed together giving rise to more inclusive categories. A category has been defined as an idea which “stands for a set of objects or events with similar characteristics—a class” (Dey, 1993, p.17). The categories in this study are mainly substantive categories, which implies that they are descriptive accounts of the participants concepts and beliefs and stay close to the data being analyzed (Maxwell, 2005, p. 97). After the process of finding and defining categories in the data was the process of sense-making. The process of sense-making involves finding connections and relationships in the data through “critical

reflection and persistent immersion in the text” (p.228) and again involves successive readings (Muller, 1999). Connecting the categories is the process of finding themes and patterns in the data (Crabtree & Miller, 1999). This is akin to quantitative studies where sense-making results through the statistical manipulation of variables. The similarities and differences that appear in the categories are identified at this stage and brought together to yield themes. Also specific cases were selected from the data in order to illustrate the range and variation of the general patterns and the underlying ideas of different cases is compared (Reissman, 2008).

The data were then reanalyzed to find narrative excerpts that best illuminate the analytical findings (Denzin, 1989). The narrative excerpts in this study are quotes from participant’s narratives or their responses to the open ended questions, which exemplify the findings for the reader. Every quoted narrative excerpt has the participant’s subject identification number in parenthesis. This makes it the excerpts easily identifiable in the original data set. The themes are main findings of the qualitative analysis and can favor the research question; however, findings can also oppose the research question as well. That is why at this stage it is important to achieve internal consistency of interpretation and search for alternative explanations (Muller, 1999). This involves searching for findings that oppose the dominant themes and making a note of them. Finally the outcome of this qualitative analysis is represented as an account of what has been learned in the researching process. The report of the findings is presented in such a way that the findings are interspersed along with the excerpts from participant’s narratives and or participant responses (Reissman, 2008). The report also includes the researcher’s interpretation and theoretical formulation as well as references to relevant prior research

and theory (Reissman, 2008). Thus, the entire report will be described cumulatively in the results and discussion section. It is important to note that this study does not aim to make generalizations across participants; rather it aims to make an in-depth description of the role that narratives play in the experience of cancer. Therefore, when describing the results, this study will note how many participants referenced a particular finding or theme; however, this study will refrain from stating how frequently that finding appeared in the data.

Overall this process of thematic analysis of the data has been described as spiral in shape rather than linear, because the researcher “repeatedly immerses him- or herself in the data, and then steps from, the data at various points in the research process” (Muller, 1999, p.229). This is an interpretive process throughout, since the participants interpret their illness narratives and the researcher interprets the participant’s stories and then reinterprets those stories for the results and discussion (Muller, 1999). The first research question also investigates experience as described in the narratives; guidelines for investigating experience are described in detail below.

**Paying attention to experience.** Narratives are considered to reflect individual experience, the way they see it as well as how they wish to present it to others, along with creating meaning in a disrupted life (Becker, 1997). This section describes the analytic approach towards studying experience in the narrative data of this study in order to answer the first research question. Looking for experience in narratives is distinguished by its “attention to the sequencing and progression of themes within narratives, their transformation and resolution” (Squire, 2008, p. 50). Clandinin and Connelly (1994; 2000) give some guidelines for studying experience in narrative data. Clandinin and

Connelly (1994) describe four directions of inquiry to understand experience which is: inward, outward, backward and forward. When looking inward, the internal conditions such as “feelings, hopes, aesthetic reaction and moral dispositions” (p.50) are described. The outward direction describes the environment and context of the story and the backward and forward directions refer to temporality, which includes the past, present and future (Clandinin & Connelly, 2000). In order to research into an experience, the researcher “must experience it simultaneously in the above mentioned four ways and to ask questions pointing each way” (Clandinin & Connelly, 2000, p.50). This is referred to experiencing an experience. A focus on ‘experience’ also tends to reduce the significance of language, “language patterns and effects tend to be uninteresting to experience centered researchers” (Squire, 2008, p.54). These strategies for studying experience in narratives served as guidelines to help answer the first research question.

**Hermeneutic approach.** This section will describe the hermeneutic approach that I will take as a researcher while analyzing the data and when presenting an account of it at the end of the results and discussion section. Clandinin and Connelly (2000) state that in “narrative inquiry, it is impossible (if not impossible, then deliberately self-deceptive) as a researcher to stay silent or to present a kind of perfect, idealized, inquiring, moralizing self” (p.62). It is important to take the hermeneutic approach in this study because the process involves improving the comprehension of a situation that has not been understood (Palmer, 1969). Also the data in this study is concerned with stories about the experience of cancer, which is a disease I have dealt with previously on personal and professional levels. I consider my training as a medical doctor, my experiences with cancer patients and witnessing my friend’s cancer experience is what I

personally bring to the hermeneutic analysis of this study. These personal insights can help yield explanations to some of the issues described by the participants of this study in relation to their cancer experiences.

Hermeneutics involves “trying to understand, take meaning from or make intelligible that which is not yet understood” (p.148), and has been described as an essential aspect of being human (Addison, 1999). Gadamer (1960) has described the process of interpreting a text as one which is within a horizon. Once the researcher starts reading and analyzing the text, he/ she apply it to their own present situation. This application results in a “fusion of horizons, in which the perspective of the text and reader are combined into a new and more encompassing horizon” (Gadamer, 1960, p.289). The central practices of grounded hermeneutic approach include maintaining a constant questioning attitude, looking for misunderstandings, incomplete understanding, deeper understandings, alternative explanations and changes with time and context (Addison, 1999). Another important aspect of the hermeneutic approach that I find important to employ in this study is the empathic stance. Taking an empathic stance orients the researchers to “other people’s experience and meaning-making, which is communicated to us through narrative” (Josselson, 1995, p. 32). The empathic stance is described as a process of “vicarious interpretation” (Kohut, 1984, p. 86) that emphasizes discovery rather than uncovering preexisting truth (Josselson, 1995). It is essential to recruit empathy into the hermeneutic approach because its “continuity and receptivity allows for a clearer perception of the internal array of another individual’s experience” (Josselson, 1995, p.31). I will present the findings from using the hermeneutic approach after describing the findings from the qualitative analysis of the narratives and participant

responses in a separate section under the heading of “personal thoughts”.

### **Reliability, Validity and Trustworthiness**

I have taken measures to maintain the quality and validity of this qualitative study. I have as far as possible I provide a rich and thick description to convey the findings (Creswell, 2009) to ensure validity of results. Conscious effort was made to present discrepant information that runs counter to the themes, thus making the findings more realistic (Creswell, 2009). Excerpts from the narratives and participants responses have been provided in order to exemplify the findings and ensure validity (Denzin, 1989). Also all of the quoted narrative excerpts have the participant’s subject identification number in parenthesis. This also enhances reliability as the excerpts are easily identifiable in the original data set. Findings from the hermeneutic approach will be presented towards the end after describing the results from the qualitative analyses to ensure that my own experiences do not color the findings from the narratives and participant responses.

Another technique I employ to enhance trustworthiness of my claims is to present my own narrative, which will provide insight into any bias that I may bring to the interpretation of the data. I have been through four and a half years of medical schooling followed by a year of internship which had rotations in all major medical specialties. Throughout my medical schooling and patient interactions, I developed a very keen interest in the patient’s experience of disease. After inner reflection, I attribute my specific interest in the cancer experience to seeing a friend of mine suffer and succumb to the disease. I clearly remember one incident when I went to visit him in one of the latter stages of disease. He found it hard to recognize me on sight because his eyes were red

and swollen, almost protruding from his skull due to papilledema (swelling of the head of the optic nerve). I was so used to seeing him laughing and being what we describe “normal”. This had a tremendous impact on me; I still vividly remember that sight and wonder what he experienced. I believe the answers to many questions in medicine lie in the patient’s experience of illness. Recent advances in the field of psychoneuroimmunology and new age concepts of health and spiritual well being point to the importance of studying diseased consciousness. It is important that I describe these perceptions I have as a researcher so the readers have a chance to discern any finding that I may bias because of my predispositions.

### **Ethical Considerations**

This study has received full approval from the Institutional Review Board of the Pennsylvania State University. I am ethically bound to the Pennsylvania State University and pledge to not misrepresent any findings from this study. The participants were asked for verbal consent as well as they had to sign a printed informed consent form to participate in this study. The completed questionnaires were stored separately from the informed consent forms. In addition, all data were stored in locked offices, and the completed questionnaires were not given any personal identifiers but instead were given identification numbers. Only the principal investigators, IRB approved research assistants and advisors had access to the data. All personal identifiers will be stripped prior to archiving. Any plans for disposing or destroying research documents will involve shredding any identifiable paper documents related to the consent process, data analysis, and report preparation and permanently deleting the records from the computer hard drive and from all backup copies. I also acknowledge the ethical responsibility I am bestowed

with to give an accurate representation of the reported narratives as well as enable a wide audience to understand the experiences in those narratives.



## Chapter 4

### Results and Discussion

#### Introduction

In this chapter, I will describe the results of the analyses that were conducted on the data. The emergent findings are presented interspersed with excerpts and examples from the data to exemplify the results (Reissman, 2008). After the results and discussion of the six research questions is described, I will provide a broader commentary related to the overall role that narratives play in the cancer experience as well as give some of my own impressions of the findings using the hermeneutic approach.

#### Research Question One: Patient Experience of Cancer

The findings in relation to the first research question yielded references to medical course of cancer such as diagnosis, treatment and prognosis. Some participants referenced the cause of cancer and expressed their views about the health care system. Participants also referenced coping aspects of their cancer experience such as social support, religion and spirituality as well referenced emotions related to their cancer experience. Finally, the participants used varied and distinctive metaphors to describe their cancer experience which are also included in the results for the first research question.

**Diagnosis.** The first finding in regards to medical course of cancer was references to the diagnosis of cancer by the participants (n=8). The first important finding in relation to diagnosis was the mention by a participant that he was “caught off guard” (P-22) by the cancer diagnosis. The participant first described himself as middle-aged and in

excellent health, after which he describes his feeling of being caught off guard by the diagnosis of prostate cancer. This suggests that the participant possibly considered his age and overall health status to be protective factors from cancer. A similar view was described in another narrative where the participant describes her friend's comment after finding out about her cancer diagnosis. The participant's friend commented that she could never get cancer because she "exercised and lived right" (P-7). This indicates that certain individuals may hold their age and overall health status to be a protective factor against cancer.

Another important finding was the participant reports of strong negative emotions in relation to their diagnosis. One participant described feeling devastated after finding out the diagnosis and described that her "whole world felt like it was falling apart" (P-9). Even in my own clinical experience, a cancer diagnosis has always been associated with a strong emotional response. At this stage of initial diagnosis, patients are known to employ various coping strategies (Morris, Woods, Davies, Berry & Morris 1992). This is evident in the data for this study as well; as a participant describes that she needed "time to deal with diagnosis" (P-12) and another participant said that she needed "time to grieve, to come to grips with it" (P-14).

Lastly an important finding is in relation to the disclosure of diagnosis to other family members. One participant expressed her anger, saying "I was angry that he gave me no time" (P-14) when her husband told the participant's family members about the cancer diagnosis too early and without her consent. The participant also describes in her narrative that after that incident she instructs all families she knows to "let the patient tell others on her/his own time" (P-14). Disclosure of diagnosis to family members is a very

important issue and family members need to be trained and instructed to have the patient's permission before telling anyone about it.

**Treatment.** References to treatment by the participants (n=10) were the next important finding in relation to the medical course of cancer. The most salient and recurrent treatment experience theme was in relation to chemotherapy (n=8). Participants described their own as well as other people's negative experiences with chemotherapy. One participant described herself "crashing" twice during her treatment and was hospitalized (P-14). Another participant described chemotherapy experience of someone else who lay with "her head in a bucket for 3 days" (P-5). Participants also expressed inhibitions and fears associated with chemotherapy (n=2) even before it was initiated. One participant describes in her narrative that she was worried about her response to chemo treatments, "having heard vague references to throwing up and having no energy" (P-16). However, the same participants (n=2) described that they responded well to the treatment and one participant even made statement that "everyone reacts differently to chemo" (P-5) After reading about chemotherapy related fears and experiences, I see a clear exigency for patient education about chemotherapy. One of the common side effects of chemotherapy is loss of hair, which was described in the narratives (n=2). However, an interesting finding in relation to loss of hair due to chemotherapy was that the participants (n=2) described cutting of the rest of their hair gave them a sense of control and is stated in the narrative as follows:

"I lost my hair. I cut off what remained and soon the stubble fell out too. I expected I would cry but I did not. Cutting off my remaining hair was quite liberating – I had something I could control" (P-14).

This throws light on the treatment experience of the participant undergoing chemotherapy, wherein the diagnosis as well as during treatment of cancer the participants felt a lack of control as well as a loss of autonomy.

The last finding worthy of mention is the overall positive attitude that was expressed for experimental treatments (n=2). One participant described that experimental treatment gave thirteen years of life to the participant's grandfather. Another participant described how her sister's best friend went to Mexico for treatments not approved in the United States and stated in the narrative that "these treatments reduced her tumors" (P-1).

**Prognosis.** References to prognosis (expected course of disease) were the next category in terms of medical course of cancer mentioned by the participants (n=3). In regards to the prognosis of cancer, the participants cited examples of people they knew who had favorable prognosis (n=2). One participant described people they knew who had a good prognosis as still "going strong" (P-16). This participant described the statement of a former employee as, "Oh, I had breast cancer 18 years ago. And I'm still going strong" (P-16). This statement was followed by a description of the participant's mother's prognosis of colon cancer. The participant described that her mother was diagnosed with colon cancer 25-26 years ago and that she was still "going strong at 84" (P-16). The participant noted that the two individuals who were in remission and "going strong" created hope for her own positive prognosis. Another participant attributed the improved prognosis of her sister's best friend to "not accepting" the doctors opinion of a 6 month prognosis and the use of experimental treatments in Mexico (P-1). In terms of outcome, this participant focused on how her sister's best friend could spend three more years with her children because of the experimental treatments.

Lastly one participant described her experience in the remission phase as being wary. She states in her narrative that, “parathyroid cancer has such a high recurrence. Right now, I’m fine, but wary, always wary” (P-13). This participant described her experience of always being on guard for possible symptoms. This indicates that even when the participant is in the remission phase, she is still not free of the disease. This is very important to understand for health care providers, that even though the cancer is in remission, the cancer might still exist mentally and or emotionally for the patient.

**Cause of cancer.** References to the cause of cancer were referenced by a few participants (n=6). Family history of cancer was most commonly referenced in the narratives which the participants attributed as a possible cause for cancer (n=4). However, there was no reference to any specific genetic or hereditary types of cancers. One participant describes her father being diagnosed with cancer at the age of 43 and her mother was diagnosed at the age of 60. This participant who presented with a complaint of neck lump to the clinic wrote in the narrative that “if I had not had family history I doubt surgery would have been ordered for a neck lump” (P-14).

Medical treatment was referenced by participants (n=2) as the cause of cancer. One participant referenced hormone replacement therapy after menopause to be the cause of her mother’s cancer by stating that, “In the early 1950s she was given hormones for menopause. This treatment was new and later proceeded to be harmful” (P-3). Another participant referenced her medication for rheumatoid arthritis as the causative agent for her cancer and stated that her B-cell lymphoma was, “caused by Rencode(sp?) an IV arthritis treatment” (P-14). In fact, this participant acknowledged the fact that she stayed on the medication longer than needed because she experienced symptomatic relief. In her

narrative, she states “I was walking normally again. I could hold a pen and write a note without pain. I pushed my luck – I stayed on the medication too long” (P-14).

Lastly one participant tried to address the issue of the cause of cancer for herself by asking a series of rhetorical questions as follows

“Did I stand too close to the microwave? Was it that unwashed apple I ate? The frog I kissed at seven hoping a prince would appear? Toxic fumes from youthful cigarettes? When did parathyroid cancer creep into my body and my life?” (P-13)

The above described excerpt indicates that some cancer patients may have answered questions regarding the cause of their cancer.

**Health care system.** The findings in the narratives in relation to the health care system were mainly negative comments by the participants (n=3) in regards to health care professionals, and individuals related to collecting bills for medical expenses. Participants (n=2) referenced the pathologist as being insensitive to the patient. One participant, who found it hard to accept her diagnosis, stated that the pathologist just looked at tissue sample of her and did not realize she was a human being who enjoyed various activities. After this, the participant asked a rhetorical question referencing the pathologist as, “does he ever wonder when he is dictating his clinical words on the page how the person who reads those words will feel?” (P-12) Another participant specifically referenced the communication that a pathologist had with the participant’s friend. This participant described that her friend who was also diagnosed with breast cancer was “informed by a pathologist in a very cavalier manner following a mammogram review” (P-17). The participant elaborated further and stated that her friend was “still very angry about how she was treated by him” (P-17) even after five years. This finding was disturbing for me

and it depicts the importance of communication skills for health care professionals. Many health care professionals in my own experience also do not realize that their actions reflect on the entire community of health care providers. The same aforementioned narrative about her friend's experience with the pathologist was described by the same participant as not worthy of sharing because it "portrays the callousness of health care providers who interact with cancer patients" (P-17) This participant also stated that it was important for her to be an advocate for herself because she "did not feel confident or comfortable in a health care provider" (P-17). This depicts the impact that communication skills for health care professionals can have for the patient's trust towards the health care system.

The last finding related to the health care system is one participant's negative experience related to individuals involved in the collection of medical expenses. The participant described in his narrative that "having to make appointments and deal with heartless bill collectors is a waste of time and energy" (P-9). After describing the interaction with the bill collectors as a waste of time and energy the participant expressed negative emotion felt towards them. This was expressed in the narrative as follows:

"Sometimes these interactions became so frustrating (on top of the stress added by having cancer) I wanted to yell and curse at all of the stoic heartless people who made things more difficult. I was supposed to be focusing on recovery, but I had to deal with the nonsense added by the other factors involved" (P-9).

This clearly depicts the immense stress that the interaction related to the medical expenses caused to this participant. It also highlights the variety of stressors that patients have to deal with in addition to their actual disease.

**Social support.** Findings in regards to social support demonstrated participant preferences (n=3) for messages and behaviors that were “responsive to another’s needs and serves the function of comfort, encouragement, reassurance of caring, and/or promotion of effective problem solving through information or tangible assistance” (Gardner & Cutrona, 2004, p. 495). One participant attributed her favorable recovery from cancer to the social support that she received from her family and friends in college. She states the following in her narrative, “They are the reason I did so well. I don’t know what I would have done without them” (P-9) in regards to her family and college friends. Another participant referenced the prayers of her family friends and co-workers as perceived social support and questions how people could face the cancer without faith. The participant describes as follows, “Looking back, I know it could have been so much worse. I had the prayers and support of family, friends and co-workers and my church family (P-14). An interesting finding in regards to social support was that one participant considered medical experts and the “sisterhood of other patients” (P-12) as social support. This participant first describes herself as “I am no stranger to cancer. I had breast cancer in 2002. I don’t count that” (P-12). The participant then gives reasons as to why she did not take her breast cancer diagnosis seriously. She describes the following in her narrative, “I breezed through same day surgery and attending fund-raising luncheons, bonding with many in sisterhood. Medical experts were everywhere and working around the clock on a cure” (P-12). Conversely, this same participant felt alone when she was diagnosed with parathyroid cancer five years after she was diagnosed with breast cancer. She describes her experience as feeling alone in her diagnosis of parathyroid cancer as follows:



“There was no parathyroid cancer sisterhood, no parathyroid cancer research dollars, no parathyroid cancer information. There is nothing. As I slid into the medical otherworld of a very rare cancer, I have no soldiers marching beside me, no sisterhood, no help. I am alone” (P-12).

This participant’s narrative elicits how the patient perceives social support from other patients who are diagnosed with a similar cancer as well as from the funding for medical research for her type of cancer.

In contrast to the comforting social support messages described above, some of the participants also had some negative experiences with their family and friends (n=3). One participant described a friend’s cancer experience where his family was not supportive of him and told him to work when he was undergoing treatment describing the example of his friend who was doing the same. The parents finally stopped telling him to go to work after the friend died of pneumonia. Another participant described the negative experience she had with her co-workers who took the participant to lunch and started discussing their own medical symptoms instead of talking with the participant. This participant expressed anger at these co-workers and questioned the intentions of her co-workers in the following way

I wondered to myself, what are they doing? Showing me they empathize because they have colds, trying to get me sick by exposing me to their colds when my immune-system is low and vulnerable? (P-1)

The participant then told them that she should not like to be around them if they have any infectious disease. This participant then compared her co-workers to another woman who had previously asked her in an insolent manner after finding out about her cancer

diagnosis, “What did you do to get that?” (P-7) To the aforementioned question the participant remarked in parentheses in her narrative, “(Like we cause these things!)” (P-7), indicating that was what she was thinking at the time but may not have verbally expressed it. Finally, one participant reported that her husband was angry at her that she “made” him cancel his commitments and appointments with church members in order to be available to her during cancer treatment (P-16). The above described findings indicate that cancer patients may be facing additional stressors even from their close social network of family and friends. The reason for the above described negative interactions maybe due to the stigma associated with cancer (Helgeson & Cohen, 1996) which may cause the cancer patients' network members to “withdraw or react inappropriately”(Helgeson & Cohen, 1996, pp.135) This is a matter of concern as cancer patients definitely need social support for psychological adjustment to the disease and treatment (Bloom, 1982).

**Religion and spirituality.** Participants (n=5) made positive references to religion and spirituality in their narratives. Specific references to God were also found in the narratives of the participants (n=4). This finding can be related to the fact that the initial recruiting was done through church organizations and 76.1% of the participants reported a religious affiliation. References to God were made in a variety of contexts with a variety of attributes given to God. One participant attributed her timely and correct diagnosis and treatment to God. The participant described that “God threw me down the stairs” (P-3) in order for her to be diagnosed correctly. In her narrative, she describes that she had three warning symptoms that were suggestive of her diagnosis of thymoma that were not given attention. So when she fell down the stairs and broke her rib, the rib

pierced through the tumor and created bleeding in her abdomen which was investigated by the surgeon and later confirmed to be a tumor. Therefore, the participant interpreted that if she had not fallen down the stairs and broken her rib, she would have not been diagnosed and treated correctly. Thus, the event of falling down the stairs was understood as a positive event that was for the benefit of the participant, who also stated in her narrative, “How lucky you can be!” (P-2) Another participant referenced God in relation to her cancer diagnosis. The participant stated that she had prayed to God for no diagnosis of cancer until her 61<sup>st</sup> birthday. She then stated that “God answers prayers, be careful how you word them. I prayed to reach 61<sup>st</sup> birthday without the diagnosis of cancer, I said no diagnosis not cancer free” (P-14). She then describes that she was diagnosed with B cell lymphoma which was caused by her arthritis medication a week after her 61<sup>st</sup> birthday.

Another important finding is the positive attributes that were given to God by the participants. One participant described that “God is very good” (P-14). This participant described that her Rheumatoid Arthritis went into remission because of the chemotherapy for her cancer, which she referenced to God as “when God blows us through a bad storm, he does give us a silver lining to the cloud”(P-14).

The last important finding in this category is that some participants deferred to God (n=2) in regards to their prognosis. One participant stated that “I have as long as God wills to continue living” (P-16) thus indicating that God would decide her future disease morbidity and mortality. Similarly, another participant stated that she would attempt to do everything in her capacity to improve the situation, but what she could not fix, she said, “I leave to others or to God” (P-02).

**Emotions.** Considering the seriousness of the medical condition that these participants were diagnosed with, the emotions that were expressed by the participants (n=4) in the narratives were mostly negative emotions. The first important finding in regards to emotion is intense anger felt about the cancer diagnosis. One participant describes stomping on the envelope that carried the details of her diagnosis. The participant states in her narrative, “I stomped on it, over and over and over until my foot hurt. Then I sobbed” (P-13) Along with being angry at the diagnosis, this participant found it very difficult to accept the diagnosis of cancer as well. In her narrative, she describes her desire to distance herself from “that ominous manila envelope” (P-13). She also referenced the envelope as not belonging “in my house, on my carpet or in my life” (P-13). This participant also referenced the pathologist who gave her the diagnosis. She described that the pathologist only looked at a sample of tissue under the microscope and did not appreciate that she was a human being who “liked popcorn at the movies”, or liked to take photographs and loved art” (P-13). Through this argument (related to the pathologist), the patient again establishes the unfairness of the cancer diagnosis for herself. Finally, the participant tried to deal with her anger at the cancer diagnosis by asking a series of rhetorical questions in regards to the pathologist, as follows: “Does he picture that person bringing her foot down on this pathology report and grinding his words to bits on her lovely Oriental carpet?” (P-13)

A noteworthy metaphor described by a participant in the narratives for a very negative emotional experience was the use of the word “torture” (P-14) in regards to her awaiting laboratory results. The participant was referring to her mental state of mind when using the word torture and it did not have any physical component to it. The

participant described the situation where her oncologist wanted a second opinion on the lab results. The participant's local lab disagreed with the original lab results so her case was referenced to a third lab which took time to confirm the findings. The participant describes in her narrative that "those two-week waits between the lab tests were torture for me" (P-14). The wait between the lab results would have created a heightened sense of uncertainty in the patient, which she felt like she was being tortured. From my own clinical experience, I can say that traditionally there is also no patient counseling during the waiting period before the laboratory reports are dispatched, which leaves the patient helplessly awaiting the results.

In contrast to the aforementioned strong negative emotions, one participant described some positive emotions as well. This could be an individual coping strategy for that participant. This participant described the emotional experience of feeling liberated after cutting off her remaining hair and getting a red colored hair wig. Along with giving her a sense of control, the participant also ascribed the action as some fun which she deserved to have. The following quote describes the participant's experience,

I lost my hair during my first trip to the hospital. It came out in my brush, it clogged the drain, but I still had some hair when I left there. I came home and cut it all off. I expected to cry, but it was very liberating – I was in control about when I would be bald. Having always wanted to be a red-head, I bought a red-headed wig. I deserved to have some fun, I thought (P-14).

The above quote also demonstrates that the participant decided to act upon a longtime desire of being a red-head after undergoing the stressful experience of chemotherapy. This indicates that patients have motivation to complete unfinished desires and business

after undergoing treatment for a potentially life threatening illness (Thomas & Retsas, 1999).

Lastly, one participant reported that her mother suppressed her emotions. When the participant's mother was asked by the doctor if she was experiencing any stress after her cancer diagnosis, the participant's mother replied that she was not under any stress at all. The participants elaborates in her narrative that as soon as her mother got into the car, "she burst out into tears and sobbed" (P-16)

**Metaphors.** Another interesting finding that emerged in the analysis of this data is the use of a variety of metaphors by the participants (n=9) to describe their cancer experience. Metaphor was defined in this study as any figurative language that compared one thing (subject) in terms of the other (frame) (Lakoff & Johnson, 1980; Bowker, 1996). The most common metaphor that was used to describe the cancer experience was the intention to "fight" the cancer (n=4). This conforms to the cancer metaphors literature which suggests "for physicians and patients alike, war is a dominant metaphor" (Reisfield & Wilson, 2004, pp.1). The experience of keeping a fighting attitude towards cancer is well exemplified by the following quote from the data: "We should all fight. Even if it means feeling confused afterwards" (P-9). It is important to note that the participant described the feeling of being confused after describing her desire to fight. This lends support to the argument that fighting or war related metaphors may not be the most suitable in cancer communication (Reisfield & Wilson, 2004). Oncology metaphors research suggests that it important to balance the instinct to fight with words of healing and acceptance (Penson et al., 2005). The participants in the narratives from this study use a variety of metaphors other than war or fighting related metaphors which challenges

the dominance of the war metaphor. In fact some participants even use metaphors with a positive or uplifting connotation.

Journey was another metaphor that was used by the participants (n=3) to describe their cancer experience. However the cancer experience journey was described as “a journey I do not want to take again” (P-14) by one participant which implicitly references the stressors experienced during the cancer experience. Another journey related metaphor that was used by the participants was roller-coaster (n=2). One participant explicated how the cancer experience felt like a roller-coaster as follows:

“Cancer turns your life into a roller coaster ride. Sometimes it is calm and you just roll along and other times its just up and down. Sometimes when your waiting on test results from your really follow ups, your life gets bumpy (ride up and down) until you get the results” (P-5).

It is noteworthy that the participant described the experience of life getting bumpy on the roller-coaster when awaiting the test results. Thus it indicates the anxiety, uncertainty and stress related to the results of the tests which the participant is metaphorically describing as a bumpy ride. Another metaphor describing a negative cancer experience was the expression by a participant who stated in her narrative that cancer made her mother feel like “rotten meat” (P-14).

One participant described her experience with having parathyroid cancer with a high recurrence is like having a “rottweiler on a short leash” (P-13) followed by stating that “right now I am fine, but I am wary always wary” (P-13). This participant draws a similarity with being watchful of a ferocious dog (Rottweiler) on a short leash which can bite any time and being wary of parathyroid cancer which can also recur at any time. In

terms of drawing similarities in experiences, some participants (n=4) compared cancer stories to childbirth stories which can be attributed to the predominantly female sample (90.5%) One participant reported that a cancer narrative she would not share with others because it reminded her of child birth stories that focused too much “on pains and contractions” (P-20)

An interesting finding in metaphors is one participant’s use of the word “adventure” to describe her cancer experience. The participant describes her approach to the cancer experience as an adventure as follows: “I approached my cancer diagnosis and treatment as an adventure, not one I chose, but since the adventure had chosen me, to ride it like the wind with whatever came along for the experience” (P-16). Conceptualizing the cancer experience as an adventure may have been a possible coping mechanism for this participant.

Lastly one participant reported a narrative that described the cancer treatment experience in an entirely metaphorical fashion as follows:

“I had a vision, a window into my psyche of what being infused with poisonous chemicals was truly like. I traversed an opaque landscape in a trance-like state for four arduous months. The sky was continually overcast. The trees were burnt, devoid of color. The terrain was rocky and hard to negotiate. No birds sang. The buildings were drab, cold cinder block structures. The people were of normal stature yet possessed blank, mask-like expressions. “Cisplatin” and “Gemcitabine” were the “medicine” that I needed to fend off the enemy that may have been lurking inside of me after my kidney was removed. This was merely a way station in my healing journey” (P-10).



The above narrative elicits the dull and depressing experience of undergoing chemotherapy by describing a dreary urban landscape and environment which consisted of an overcast sky, burnt trees and individuals with no expressions.

The results to the first research question definitely elucidate the complexity and nuances of the cancer experience (Harter, Japp & Beck, 2005) for the participants in this study. The narratives revealed findings related to the participant's diagnosis, prognosis and treatment as well as brought up issues related to the cause of cancer, social support and the health care system and addressed existential and emotional issues. The findings thus demonstrate to us how complex the cancer experience can be for individuals (Carlick & Bailey, 2004) as well as how the narratives served to bring forth unique aspects of the individual experience (Baktin, 1981; Vezeau, 1994) in regards to cancer. Distinct aspects of the individual experience previous life experiences were used to create meaning and understanding (Baktin, 1981; Vezeau, 1994) which is demonstrated by the use of metaphors and comparing the cancer narratives to stories about childbirth.

The unique metaphors and perceptions of the participants of this study also confirm the assertion that individuals experience their illness in very subjective ways (Pierret, 2003). The findings related to the cancer experiences of these participants; such as the negative emotions felt at the time of cancer diagnosis, suggests that diagnosis of cancer can be a cause for great anxiety and uncertainty for patients (Salander, 2002). In terms of dealing with the cancer, the patients references to faith, God and prayer substantiates previous research which suggests their importance in giving patients "strength" to deal with cancer (Overcash, 2004). The references to social support which featured in the narratives of this study have also shown to be "extremely important"

(p.51) for patients in their cancer experience (Van Der Molen, 2000).

The cancer patients in this study described their experience with range of metaphors; one metaphor even had positive connotation. These metaphors challenge the predominance of the war metaphor in oncology (Reisfield & Wilson, 2004) and can give way to more individualized metaphors for cancer patients, as well as metaphors that indicate healing and acceptance (Penson et al., 2005). Finally, it is important to note that even though some cancer patients described the importance of keeping a positive attitude or a “fighting spirit” (Greer et al., 1990) in their cancer experience, this attitude may not be suitable for all patients. In fact the findings confirm that some patients did not approve of being positive all the time, or keeping a fighting attitude. This suggests that the ways in which the patients deal with cancer must be left to them, and patients should not feel compelled to adopt a particular coping style (Petticrew et al., 2002). These findings have implications for the use of illness narratives in medical care of cancer patients; these implications will be dealt with in the next chapter.

### **Research Question Two**

This research question attempts to understand the differences between the narratives that the participants described as worthy of sharing and those that were reported as not worthy of sharing. Overall the stories described as worthy of sharing had positive statements and were potentially uplifting while the stories to not share had mainly negative references.

**Stories to share.** A total of 27 narratives were reported by the participants (n=16) as worthy of sharing. An important theme that emerged in the stories to share was that related to the notion of “triumph over adversity” (n=3). Participants ascribed to the

fighting metaphor to describe triumph over the adversities faced because of the cancer. The participants described the importance of keeping a “fighting” attitude against all odds. This is clearly seen in this following participant response, “not knowing is normal, feeling helpless is normal but the ability and the desire to fight is also normal. We should all fight” (P-9). In this excerpt, we see that after the participant describes the adversities faced in terms of uncertainty and the feeling of helplessness after which the participant introduces the notion of fighting and not surrendering to the adversity. One participant described her aunt’s cancer narrative and the outcome of her keeping a fighting attitude, “The cancer she had was fatal, but she fought and spent another 3 years living with her children” (P-1). Due to the immense psychosocial trauma induced by cancer, patients often take the stance of strong optimism which can be source of strength and courage in the time of adversity (Miller, Manne, Taylor, Keates, & Dougherty, 1996). Some participants took this notion of not surrendering to adversity to not accepting the doctor’s word. The same participant describes in her narrative as “The doctors told her she only had six months to live at most, and sent her home to die. She did not accept this” (P-1). She then describes how her aunt took experimental treatment which helped her live longer.

An important finding that emerged in contrast to the triumph over adversity theme was the participants expressing the “need to relax and focus on their health instead of fighting” (n=2). Participants counteracted the idea of taking a fighting stance and described the need to relax and focus on their health and peace of mind as the right attitude to take when diagnosed with cancer. In the following excerpt the participant stated that, “I don’t need a lifetime achievement story done on me about how I soldiered

and triumphed all odds during treatment. I just need to get healthy and then get on with other things once the health is returned” (P-1). It is noteworthy that the participant (P-1) who reported in her story to share mentioned the positive outcome of her aunt’s fighting attitude towards cancer. However when describing her own cancer experience she defined the need to relax and focus on her health to be more helpful. This demonstrates that having the attitude of triumph against adversity may not be suitable for all individuals. In fact, in some cases this can be forced on the patient like the example of one participant who described a situation when the cancer diagnosis was revealed to family members by her husband without her consent. The participant reports that she “had to sound upbeat for them” (P-14) and was angry at her husband that he did not allow her time to deal with it on her own. This is consistent with research that suggests people with cancer have distinct and individualized ways of dealing with the condition (Petticrew, Bell & Hunter, 2002).

**Stories not to share.** Stories reported as not to share by participants (n=13) comprised of 18 narratives. In the stories to not share, participants reported stories containing the descriptions of negative cancer experiences (n=9). For example, one participant wrote a personal experience that she reported as a story she would not share with other cancer patients because it was “a very unpleasant time.” The participant described the following in her narrative.

“After my second chemo Rx I got really sick. In fact, I ended up in the hospital for 7 days with an infection. Turns out I also developed colitis. This, along with the cancer, has affected my life on a permanent basis. I know can not eat some of my favorite foods because of it” (P-12).

Similarly, another narrative by this same participant described the narrative of a co-worker diagnosed with cervical cancer as a story to not share with others because “her focus was on the negative” (P-12). One participant describes the narrative of her colleague’s wife as a story she would not share as it “was filled with everything that went wrong – surgery complications, problems with chemo and radiation made everything worse” (P-20). Another noteworthy mention is a narrative reported by a participant as not worthy of sharing because it had “every horror story of her diagnosis, treatment and surgeries” (P-21). This participant further elaborated her own emotional reaction of feeling discouraged after listening to the individual’s “horror story”. It is also noteworthy that some of the participants (n=2) attributed the stories about negative experiences as a result of the narrator’s focus on the negative experiences despite having a good prognosis.

The next important finding in the stories described as not to share was the description of negative patient outcomes (n=4). One participant reports her mother’s narrative as “not encouraging” (P-3) after which the participant describes how the mother broke her hip and finally died of pneumonia. Another participant reported the story of her sister’s diagnosis with Hodgkin’s lymphoma and subsequent death after four years as a narrative she would not like to share with others. Lastly one participant asserted in her narrative that she did not like “cancer stories about the ones who have lost the battle” (P-5).

Other noteworthy finding were that one participant referenced individuals who went against standard medical treatment in her story to not share. She described the example of a woman who “second guessed all doctors” (P-2). She also described people

who believed in self-healing as scary because “it can kill them” (P-2). Thus this participant implicitly describes the importance of following prescribed medical treatment. Lastly one participant referenced some blogs on the internet that she described as “distasteful” in the narratives to not share. This participant described her anger at the excessive optimism that was expressed by the members of the blog. She reported in her narrative that some of the blog members wrote that “cancer is a great disease because chemotherapy gives you a smooth complexion” (P-15). This participant also justified for herself at the end of the narrative that it is normal to feel angry when diagnosed with cancer and referred to the members of the blog as “delusional” (P-15).

The findings for the second research question highlighted important contrasts in the participant’s views and opinions expressed in the stories to share and not share. While some participants found it important to maintain a heroic attitude (Frank, 1995; Ezzy, 2000) other participants described a need to relax and be at peace. In the stories to not share most of the narratives were about negative experiences and negative patient outcomes. This is an intuitive finding when we consider the grievousness of the disease. The finding can also be understood as patients wanting to share positive narratives that have the potential to generate hope in the readers, and not share stories that diminish hope for the reader (Felder, 2004). However even in regards to not sharing negative experiences one participant considered individuals with an overtly positive attitude in regards to their cancer as “delusional”. This indicates that patients choose “different strategies to cope with their life situation” (Kvale, 2007, pp.321) and positive coping strategies may be not be well suited for all individuals.

### **Research Question Three: Reasons to Share or Not Share Stories**

This section describes the findings from analyzing the participant's responses to the open-ended question of why they would want to share or not share the narratives reported by them.

**Reasons to share stories.** In the reasons to share the story about cancer the first finding was related to creating a sense of social support (n=6). Participants implicitly referenced how the narrative could serve as emotional social support (n=2) as well as informational social support (n=2). In reference to emotional social support one participant stated that the narrative will “help other cancer patients cope with their disease” (P-13) and also create a way for those in “cancer world to bond” (P-13). These above statements give explicit support to the theory that suggests that narratives can serve as a way to help cancer patients cope with their disease (Carlick & Biley, 2004). Similar to the aforementioned statement another participant described that “sincerely connecting with a patient and survivor” (P-17) through narrative could provide encouragement to those individuals diagnosed with cancer, which again references emotional social support. Participants who referenced informational social support mentioned that the narrative will tell people “things they need to know and think about” (P-15). Similarly another participant described the reason to share the narrative is that “it’s good to know what to expect” (P-19) after which the participant stated that reading other peoples narratives gave that participant “all the perspectives” (P-19). Other participants referenced the general significance of social support in their responses by stating the importance of a “good support system” (P-9) and the “importance of sharing the diagnosis with family members” (P-21).

Some participants reported narratives containing positive outcomes as a reason to

share the cancer stories with others (n=3). One participant explicitly mentioned a good prognosis in her response and stated that she would like to “explain that there is life after cancer – even a very long life” (P-3). Another participant referenced how the narrative can elicit hope. When reporting the reasons for sharing the story, this participant reported, “Hope – there is always hope you will be that small % that beats the odds” (P-2). This suggests that patient narratives can serve the function of creating hope for other patients (Harper-Chelf, 2000).

Participants also referenced wanting to communicate stories about informed decision making as a reason to share the narratives (n=2). One participant described how she researched her options and went into her treatment “well-versed” (P-28). Another participant stated that the narrative shows the reader that “we should not just accept what doctors tell us” (P-1).

Finally, some participants dispensed advice and information that they would like to share with other cancer patients in their responses (n=2). One participant advised other cancer patients to “stay calm and take one day at a time” (P-5). This participant also conveyed a warning to other cancer patients that they would hear both good as well as bad stories but to keep in mind that “everyone is different” (P-20). Another participant wanted to convey to others that it is possible to be diagnosed with cancer in any stage of life.

**Reasons to not share stories.** In the reasons to not share a narrative, the participant reports contributed the following three major findings. The first was that participants did not want to share the narrative because they thought it was depressing (n=4). One participant described an implicit understanding that anyone with a diagnosis



of cancer would already be depressed and therefore they did not want to share a story that would “depress them even more” (P-5). Related to this finding was that one participant gave their reason to not share the narrative because the narrative gave little hope to others. This again confirms that narratives may serve to be a way of creating hope for other patients.

The second finding in the reasons reported to not share a story was that the participants believed that the focus of the story should be on the positive and not the negative (n=3). One participant reported that she believed that it is “so very important to focus on the positives and not the negatives” (P-12). Similarly another participant reported the importance of focusing on positive experiences especially during the early stages of diagnosis because “dealing with negativity only makes it worse” (P-21). This confirms previous research that shows that patients consider maintaining a positive attitude an important component of “beating” cancer (Overcash, 2004).

Lastly the participants reported the reason to not share the narrative was because it reflected poorly on the health care system (n=2). One participant referenced the health care providers and states that the narrative “portrays the callousness that I hope is not generally true about health care providers who interact with cancer patients” (P-17). Another participant referenced the general discipline of medicine and stated that she would not share the story because it “illustrates how medicine can harm as well as cure” (P-3).

The findings in regards to the third research question yield mostly altruistic motivations to share or not share cancer stories. In the reasons to share participants described wanting to create a sense a social support, sharing positive outcomes to incite

hope, share information and incite informed decision making. The reasons to not share were related to the stories being depressing and focusing on the negative instead of the positive. These results thus implicitly reveal the empathy that the participants had for other cancer patients that they wanted to convey through their narratives (Keen, 2006). These findings also suggest that patient's in this study viewed their narratives as potential ways of coping with cancer as well as generating hope for other cancer patients (Carlick & Biley, 2004; Harper-Chelf, 2000).

#### **Research Question Four: What Do You Want to Read in a Story about Cancer?**

In response to the question of what the participants wanted to read in a story about cancer, information in regards to treatment (n=5) was an important finding. Some participants (n=3) specifically mentioned that they wanted to read about new treatments or “advances” (P-19) in treatments or “unique” (P-21) treatment options. This indicates that participants were motivated to be informed about the advances in cancer treatment. Participants (n=2) also wrote that they wanted to read if the treatments actually worked, implying the effectiveness of the treatments in terms of patient outcomes. One participant described wanting to read about “helpful tips” (P-5) in regards to dealing with the cancer treatments. Finally one participant wrote that she wanted to read that “life can return to “normal” after successful treatment” (P-1). The above findings indicate that treatment related information was sought after as well as considered important by some of the participants.

Another important finding in the findings for research question 4, was that the participants referenced wanting to read cancer related information in the narrative (n=5). Some participants did not elaborate on the content of the information they wanted to read

in the narrative (n=2) but described the quality of the information they wanted to read by referring to it as “accurate facts” (P-13) or “solid” (P-17) information as well as the nature of the information (n=1) described as “positive” (P-16) information. Other participants (n=2) described that they wanted to read about “what to expect” (P-19) in the narrative, implicitly referencing the process of cancer diagnosis and management. Related to the above mentioned finding about participants seeking cancer related information in the narrative is that participants (n=2) stated that they wanted to read about patients making informed decisions in a story about cancer. The above findings clearly indicate that cancer related information was given considerable importance by some of the participants in the study.

The next important finding in this section is that participants described that they wanted to read about cancer survivors (n=4). One participant referred cancer survivors as “the people who beat it” (P-22) while another participant referenced wanting to read about individuals who had survived cancer and “are now doing well” (P-9). Another participant referenced how the survivor stories are related to hope for her. Finally one participant described cancer survivorship stories as “happy endings” (P-28). In relation to cancer survivorship some participants also reported that they want to read stories about how families coped with the cancer (n=2) as well as how cancer patients coped with the cancer (n=1) and some coping strategies to deal with the cancer (n=1).

Lastly, some participants wanted to read stories about cancer that were tailored to a specific audience (n=2). One participant described wanting to read cancer stories for adults that were written at the third grade reading level as well as stories that were suitable for those who spoke English as second language, thus implying more simplicity

in the language of the cancer narrative. Another participant wanted to read a cancer story from a religious standpoint and described her own narrative from a Jewish woman's perspective. This participant further elaborated in her response how her two major surgeries and four months of chemotherapy coincided with Jewish holidays. These findings indicate that some participants felt the need for audience adaptation in their expectations regarding a story about cancer.

The findings related to research question four reveal important insights regarding the desired content of cancer narratives. The findings confirm that patients seek treatment related information and want to know what to expect in terms of the course of illness (Hawkins, 1999). Many participants explicitly wanted to read about cancer related information suggesting that if patients have a high need for information through narrative then narratives can possibly help facilitate information processing (Kreuter et al., 2007). The finding which was related to participants seeking to read narratives about cancer survivors lends evidence to the idea that narratives can serve as social support through para-social interaction (Kreuter et al., 2007). Para-social interaction essentially means the process of the reader identifying with the character (s) within the narrative (Rubin & Perse, 1987)

#### **Research Question Five: Benefits of Narrative Sharing/Writing**

In regards to narrative sharing and or writing, participants reported some perceived benefits (n=3). One participant stated in parenthesis after describing her narrative that, "I realize this story was disjointed and rambled on, but it felt good to get off my chest" (P-9). This indicates the participant experienced some emotional relief after narrating her story in written form for the purpose of this study (Pennebaker & Seagal,

1999). Similarly one participant reported her initial struggle to bring voice to her cancer experience which had ended seven months ago. She then stated in her narrative that “I am elated now that I am able do so” (P-10) in reference to being able to share her cancer experience in the narrative. Another participant described that her narrative helped assert for herself that “it’s okay to be angry” (P-15). She also attributed the freedom to be angry as a source for her inspiration to fight. She stated the following in her narrative “How else are you going to keep up the strength to fight such a devastating disease and the hope to win?” (P-15) The above findings corroborate well with literature that suggests that writing narratives serves the function of organizing complex emotional experiences and thus the emotional effects of that experience become more manageable (Pennebaker & Seagal, 1999).

#### **Research Question Six: Benefits of Narrative Listening/reading**

In regards to the benefits of narrative listening or reading, the participants reported how the narratives positively impacted the appreciation of their social support network (n=3). One participant stated in her response that the events in the narrative “made me realize how fortunate I am to be surrounded by good people” (P-9). Similarly another participant described how the narrative increased the “appreciation of my family and my friends” (P-28). Lastly one participant reported that reading the narrative made her “feel less alone” (P-13).

An important finding in relation to the benefits of narrative listening and or reading was the positive impact the narratives had on the participant’s attitudes towards life (n=6). One participant described the events in the story made her “remember that each day is a gift” (P-1). Similarly one participant described that the narrative she

reported put a “positive spin on my unexpected adventure” (P-16) in reference to her cancer experience. Another participant described how the narrative made her realize the importance of being optimistic and “to be able to live with ambiguity” (P-3). One participant stated that the narrative influenced her to “stay calm and experience things” (P-5) for herself. Finally two other participants referenced how the narratives reinforced the strength in them to face the cancer.

One participant described a more pragmatic benefit that the narrative had that it made her realize that she had to be a self-advocate in terms of choosing a suitable health care provider. This participant further elaborated and stated that if she “did not feel comfortable or confident in a health care provider” (P-17) she would search for someone else. This suggests that narratives can have benefits in terms initiating informed decision making in some patients.

Lastly an important finding contrasting the above findings was the response by a participant who decided to “stop reading real life blogs and concentrate on medical research instead” (P-2) when asked if the narrative they reported changed anything in the participants life. This indicates that personal narratives may not be well received by all cancer patients. Another participant reinforced this finding by stating that she did not read the net for cancer information with the exception of certain websites she defined as trustworthy such as the National Cancer Institute and the National Comprehensive Cancer Network.

In the findings for the benefits of narrative listening or reading, participants described their enhanced appreciation of their social support network which corroborates well with the notion that narratives can be beneficial to individuals because they serve the

function of connecting people (Sunwolf & Frey, 2005). The next important finding was that participants reported that the cancer experience had a positive impact on their attitude towards life. This supports previous research that suggests that the cancer experience can help patients find meaning in their lives (Lin & Bauer-Wu, 2003) “in spite and because of suffering” (Kreuter et al., 2007, p.228). Lastly an important finding was related to information and narratives. A friend’s cancer narrative helped one participant take the attitude of informed decision making and some other participants sought more credible sources of information. The finding related to information in narratives agrees with the view that narratives can serve the function of explaining (Sunwolf & Frey, 2005) as well as transmitting knowledge and information (Harper-Chelf et al., 2000).

### **Role of Narratives in the Cancer Experience**

This study advanced six research questions in relation to the cancer narratives and the participant’s responses as presented above. However an overarching question that this study asks is about the role that narratives play in the experience of cancer. The results from this study suggest that narratives played an important role in coping with cancer and had certain benefits for participants of this study.

Cancer information featured as an important component of what the participants wanted to read in a story about cancer. Participants specifically referenced wanting to read treatment related information in terms of advances and ways to deal with cancer treatments. Participants also referenced the quality of the information they wanted to read to in the narratives in terms of accuracy and credibility. In fact one participant referenced the National Cancer Institute and the National Comprehensive Cancer Network as trustworthy sources of information. These findings confirm that cancer patients have

important information needs (Van Der Molen, 1999; 2000). The findings also reaffirm that narratives are a good medium to transmit cancer information to individuals (Harper-Chelf et al., 2000).

Another important finding of this study is the overall inclination that the participants had to create a sense of hope in their cancer experience. Some narratives reviewed individual's life and highlighted achievements and human values to restore dignity taken away by cancer (Chochinov, 2002), such as the narrative that described the participant's aunt who faced the cancer in order to be with her children for three more years. In some of the narratives individuals depicted themselves as heroic characters that "triumphed over adversity" and used fighting metaphors that elicited how they dealt with their cancer (Frank, 1995; Ezzy, 2000). Participants indicated that they wanted to read about cancer survivors who had successful remissions and a "happy ending", as well that that life can return to normal after treatment. Even in the stories to share cancer patients indicated that would want to share positive and uplifting stories and they would not want to share negative stories that give "little hope". These findings confirm that hope is considered to be very important by cancer patients (Delvecchio Good et al., 1990; Chi, 2007). The finding also lend support to the proposition that content of cancer narratives serves to foster hope in individuals affected by cancer (Harper-Chelf, 2000).

The findings also suggest some perceived benefits from the narratives for the participants. Participants expressed relief after expressing their thoughts and emotions in their narrative, like the participant who said she felt "elated" after being able to convey her story. This confirms previous research about narrative having the potential to help people express emotions as well as make the emotions more manageable (Pennebaker &



Seagal, 1999). Reading the narratives also had certain benefits such as a more positive attitude towards life (Lin & Bauer-Wu, 2003). These findings indicate that the narratives served to benefit and inspire the narrator of the story (Pennebaker & Seagal, 1999) as well as the audience (Radley, 1999). An interesting finding in terms of narrative benefits was the mention that the narrative enhanced the appreciation of their social support and even made one participant feel “less alone”. This finding is also found in the reasons that participants gave to share their narratives. Participants (n=6) mentioned that they would want to share stories with other cancer patients because it would create a sense of social support. This lends support to the idea that narratives create a sense of connection between the narrator and the reader (Sunwolf & Frey, 2005) possibly through relating to the narrator via a pseudo or para social interaction (Kreuter et al., 2007). All these findings suggest that the role that narratives played in the experience of cancer for these participants is that of helping them cope with the cancer. Thus this study lends support to the theory that proposes narratives can help cancer patients cope with their illness (Carlick & Biley, 2004). This theoretical implication will be dealt with in the next chapter.

### **Personal Reflections**

The findings from this study demonstrate to us the various aspects of the cancer experience and highlight the distinctive ways in which the participants of this study experienced their cancer. During my medical school training, I was taught that cancer has a tremendous psychosocial impact on the patient and this must be addressed during management of the patient. However, after reading these narratives I realized how superficial that instruction is, because psychosocial impact cannot be understood without

appreciating the aspects of the patient experience of disease. In this section, I will also discuss my own impressions after studying these narratives in terms of my training as a medical doctor, my experiences with patients, witnessing my friend's cancer experience and my own experiences.

I could understand to a certain extent why one participant expressed cutting her remaining hair after chemotherapy as a form of exercising control. This can be attributed to one extent as the patient's desire for control in a life that is disrupted by disease (Frank, 1995). However from a clinical perspective I can attest to the fact that patients feel a loss of control and autonomy right from the time of diagnosis and throughout the treatment as well. Even if the patient has made an informed decision and has expressed his/her choices regarding treatment, the method through which the treatment is dispensed inadvertently causes the patient to feel out of control. Chemotherapy is administered mainly through an intravenous catheter which is essentially a flexible plastic cannula mounted on a metallic needle. Generally the patient's peripheral vein is pierced to accommodate this intravenous catheter and administer the chemotherapy drugs. All these procedures have a specific protocol and the patient is a passive recipient. Even though the patient is verbally informed what is going to happen in each step, the patient is still submitting his/her body to the health care professional in each step therefore losing control of themselves. It was not until I had surgery myself that I realized how much I had to surrender my own body to the health care professionals.

Another important finding that connected with me was the references to God in the narratives. I have interacted with many patients who attribute their prognosis and recovery to God. I have personally heard many patients repeat almost the same exact

sentence that was described in the narratives as “I have as long as God wills to continue living”. Again religion and spirituality can be understood as a coping mechanism for cancer (Lin & Bauer-Wu, 2003). However since my own sense of spirituality has grown I can say that submitting to “God’s will” can actually create a sense of freedom for the individual because they know that God is always taking care of them.

I also find it important to discuss the finding related to the “triumph over adversity” attitude that some participants expressed. This may lead us to think that cancer patients might find it important to hold an attitude of an almost unabashed optimism in order to create hope in a disrupted life. However some types of cancer can produce a feeling of helplessness in the patient because of the lack of effective treatment modalities. As human beings it is hard to give up when it concerns one’s own life or the life of a loved one. My friend, who was a medical student in the medical school that I attended, was diagnosed with a rare type of cancer. He was trained in the western bio-medical model of disease diagnosis and management and his father who was a surgeon was also trained similarly. India has a large variety of healing modalities available to the population of which western medicine is still the dominant modality. Traditional healing modalities and the so called “faith” healers are not very appreciated within communities of health care professionals that practice western medicine. So when my friend’s chemotherapy and radiation failed to treat the cancer, he and his family decided to go to a faith healer for treatment. This was a matter of surprise for me and my friends in medical school and we understood this decision as a last attempt by the family to maintain hope in a time of crisis. After reading the narratives in this study however I can also see how it is important for individuals to take actions in their own ability in order to avoid feeling

helpless. What we see may see as attitude of unabashed optimism can also be interpreted as an attempt to restore the feeling of self efficacy.

The findings also suggest that along with keeping an attitude of triumph over adversity some participants tried to avoid the description of negative experiences. Initially I thought that patients were attempting to block out the negative aspects of the disease experience so they could remain optimistic about their own prognosis. However, during my own inner reflection I realized that this could possible be because the stress that disease induces makes the individual's consciousness very sensitive to other individual's stories. I was hospitalized for a fracture and dislocation of my ankle for five days during the beginning of my medical school. During my stay at the hospital I met another patient there who told me the story of how his foot was crushed into pieces because he accidently stuck it into a grinder and was in the hospital for five months. At that moment when I was recovering from my surgery and that story disturbed me a lot because I could feel the pain and suffering of that other individual but at the same time did not want it to happen to me. This helped me understand the references made in the data for this study that mentioned avoiding stories that described negative experiences.

After studying the narratives in this study, I could relate to cancer patients more, understand the complexities of their world and the diverse issues faced by them. The narratives definitely gave me a "window" (Hawkins, 1999, pp.129) into the experience of cancer which was not available to me even after five and half years of medical training. Patient narratives hold promise as tools of perspective taking for doctors, especially oncologists. These narratives have definitely influenced the way in which I understand the disease of cancer and its impact on patients. Reading these cancer narratives has also

made me realize that even during disease and infirmity the human spirit still finds ways to express itself. It is imperative that we stimulate further research in cancer narratives and some possible directions are discussed in the following section.

## Chapter 5

### Implications, Limitations and Conclusion

#### Implications

This section discusses the practical as well as theoretical implications that this study has in regards to previous research. This section also describes some possible directions and cautions for future research.

**Narratives in cancer care.** The medical management of cancer is a very challenging task for physician's right from the time of diagnosis till throughout treatment. The physician has to consider everything for the cellular morphology of the cancer, possible metastasis, grading and staging the cancer to the specific doses of the chemotherapeutic drugs. At the same time, the physician has to also monitor the patient in terms of immunologic response to the treatment and manage potential side effects. In this complex system of the medical management of cancer, where the ultimate goal is a cancer free patient, what the patient is experiencing in this mayhem almost seems trivial and is routinely ignored by physicians (Coulehan, 2003). Even if the physician is interested in learning about the patient experience, there are many institutional and pragmatic constraints to this endeavor. Articulating illness experience is a difficult process and takes time, this time can be more productively spent in taking the medical history and performing procedures which assist the physician in the management process. Patient narratives of cancer have the potential of bridging this gap and help physician's gain perspective of the cancer patient's experience.

After reading these narratives, I realized a host of factors that I was oblivious too

in my medical training. Medical tests normally do take at least a week time to be confirmed by the laboratory. I realized that this seemingly normal wait time, could be experienced as “torture” by the patients. Certain patients found it important to keep a fighting attitude, while others did not. Before reading these narratives, I could never have imagined that a patient would liken parathyroid cancer to a Rottweiler on a short leash. The participants used idiosyncratic and varied metaphors like roller-coaster, journey, and adventure to describe their cancer experience. The patient experience of cancer was highly contextualized in the lives of these participants (Hyden, 1997) and narratives are way of understanding the patient perspective of cancer. Reading narratives of cancer experiences from patients could definitely be beneficial for oncologists and other health care providers involved in the management of cancer patients. Health care providers can read these narratives of cancer experience and realize the complexities of the cancer experience. Moreover the results highlighted that the patients were also struggling with issues of identity of being diagnosed with cancer. This is seen by the discord in their opinions as to why they would share their cancer stories as opposed to what they wanted to read in a story about cancer. When expressing the opinions about what they wanted to read in a story about cancer the participants resumed the identity of the diagnosed patient and asked about treatments, information and advances. But when asked to provide motivations to share their story they assumed an identity of an altruistic survivor who wanted to help others in their suffering.

Narratives are also a very pragmatic way for health care providers to study cancer experience. Patients can write these narratives at their own convenience, and present them to the health care providers. Therefore, there is no investment of time from the

health care providers in eliciting experiences from the patients. Along with being present to the host of complexities and nuances in the patient experience of cancer, health care providers can better understand patient needs from these narratives as well. However it is important to note that the sample for this study was mostly well educated patients who had a previous diagnosis with cancer. The ability and willingness to write narratives can well be attributed to the level of education of individuals. Therefore individuals who may have lower education background can be given opportunities to orally express their narratives. Another cautionary standpoint that needs to be adopted in the use of narratives in oncology care is that patients may have reservations about writing or expressing their narratives based on the audience that is going to read their narrative. Utmost confidentiality must be maintained and the patient must be told as to who is going to read or listen to their narratives.

Participants in the narratives specifically referenced the “callousness” of health care providers while disclosing diagnosis. This may seem disturbing to the reader; however, health care providers can actually do something to remedy their behaviors if they read about them from the patients in their narratives. I was concerned that one participant was delivered her cancer diagnosis when the participant was driving. The health care provider should have inquired what activity the patient was doing before delivering the diagnosis. It is understood in medical protocol that delivering a serious diagnosis such as cancer when the patient is driving is never a recommended situation for disclosure. This finding would definitely have concerned any health care provider in oncology, if they had read these narratives. Also some participants explicitly referenced that it was important to not accept the doctor’s statement as final. This could be



considered as good attitude if it promotes patient autonomy and informed decision making. However it can also be potentially risky if the patient decides to go against recommended medical treatment. Therefore health care providers can thus learn what the patient perceives about his/her treatment through patient narratives. Thus we see that patient narratives can serve as a way of vicariously experiencing the world of the cancer patient (Hawkins, 1999). The study confirms that medicine is losing out from learning valuable information about the patient experience of cancer by not including patient narratives in medical care (Greenhalgh & Hurwitz, 1999; Coulehan, 2003).

This study recommends future research into the benefits of incorporating patient narratives in oncology care to enhance taking the patient's perspectives and experiences. Future research should measure the benefits of incorporating narratives for the health care providers as well patients. Studies in the future should also have more in-depth interviewing techniques to better understand the contexts and explanations for cancer patient experiences. An impetus for health care providers to include narratives in oncology care is that this study confirms that narratives can help patients to cope with cancer.

**Narratives and coping with cancer.** The participants of this study referenced cancer narratives as a way of dealing with cancer. Along with helping in emotional regulation, the narratives also created sense of social support and were considered a medium for obtaining information. All these findings are evidence to support the theory that suggests that narratives can help cancer patients cope with their disease (Carlick & Biley, 2004). This theory suggests that narratives, as a medium, can help patients cope with cancer through problem-focused coping as well as emotion focused coping (Lazarus

& Folkman, 1984). Due to cancers unique psychosocial impact on patients, coping strategies for cancer patients have demonstrated to be different than other chronic stressors or chronic illnesses (Lin & Bauer-Wu, 2003). Cancer patients have been known to use strategies such as “fighting spirit” attitude (Greer et al., 1990), religious faith and spirituality (Lin & Bauer-Wu, 2003), and social support (Felder, 2004). Narratives have been posited to help patients cope with cancer (Carlick & Biley, 2004) based on the transactional model of coping and stress (Lazarus & Folkman, 1984). However, there is little empirical research done in the context of cancer to back the theory of narratives as medium of coping with cancer (Carlick & Biley, 2004; Kreuter et al., 2007). The results of this study give support to this theory and demonstrate how narratives help cancer patients cope through problem-focused coping as well as emotion-focused coping.

*Narrative and problem-focused coping.* Problem-focused coping involves doing something constructive and comprises of objective information seeking and decision making (Lazarus & Folkman, 1984). The results demonstrate that participants sought information from the narratives and one participant explicitly mentioned that reading her friend’s narrative helped her make informed decisions about her treatment. Participants specifically sought treatment related information in terms of advances and stories of successful treatments. This suggests a problem-focused coping strategy, since it involves the impetus to actively procure information that reduces the stress caused by the diagnosis of cancer. The knowledge that other individuals diagnosed with cancer have been successfully cured can reduce the patient’s anxiety and foster hope. The results thus suggest that content of narratives can serve to generate hope in cancer patients.

Participants reported narratives that were positive and uplifting as worthy of sharing and

negative stories as not worthy of sharing. This bias towards positivity again suggests that cancer patients seek to foster hope not only for themselves, but also for other cancer patients. Levels of hope and levels of coping in cancer patients have been shown to be correlated and hope is considered to be intertwined with coping (Felder, 2004). This study contends that narrative content can assist patients to cope with cancer through creating a sense of hope. Hope can be understood as a problem-focused strategy as well as a emotion-focused strategy. This study demonstrates that patients look to create hope through cancer information, which is a problem focused strategy. The study also demonstrates that participants wanted to read about successful and healthy cancer survivors, suggesting a strategy of positive comparison, which is a emotion-focused approach (Folkman & Lazarus, 1984).

*Narrative and emotion-focused coping.* Narratives functioned as a way of emotion-focused coping as well. Individuals reported perceived benefits of expressing their emotions and experiences during the narrative writing process. Emotion-focused coping is concerned with reducing and managing emotional distress (Lazarus & Folkman, 1984). The participants explicitly referenced feeling “elated” and “good” after writing their narratives, which confirms research that describes health benefits of narratives. The results also suggest that narratives can assist in emotion focused coping by creating a surrogate sense of social support (Heiney, 1995), referred to as para-social interaction (Kreuter et al., 2007). Social support has shown to be an important moderator of emotion based coping for cancer patients (Spiegel, Bloom, Kraemer & Gottheil, 1989). In the reasons to share narratives, the participants referenced that their stories could create a sense of social support. This perceived social support helps cancer patients in their

emotion-focused coping.

This study lends qualitative evidence to support the theory that narratives can help cancer patients cope (Carlick & Biley, 2004). One participant explicitly states in her reason to share her narrative that the narrative could help other patients cope with cancer. This study has shown that narratives helped cancer patients in this study cope through problem-focused as well as emotion-focused coping strategies. A major strength of this study is that it was conducted in the context of actual cancer patients. However the results and implications of this are outcome of an inductive analysis of cancer patient narratives and responses to open ended questions. Future studies need to specifically question participants about their attitudes, beliefs and behaviors in regards to narratives. Future studies should also quantitatively determine the coping benefits of narrative writing/sharing and narrative listening/reading separately.

**Narrative information and public health communication.** The finding related to the importance of transmitting health information through narratives has important implications for public health communication as well. Narratives have been posited to be potential source for dissemination of health information (Kreuter et al., 2007). Individuals found a decrease in perceived barriers to cancer screening when the information was presented in a narrative form (Dillard et al., 2010). The findings of this study indicate that some participants wanted to read narratives to learn what to expect from the illness experience. This confirms that narratives serve as potential guidebooks in the illness experience (Hawkins, 1999). Narratives of illness and health information can serve as important tools for channels of public health communication. Public health research indicates the importance of boosting health literacy in cancer patient populations to

increase patients understanding of cancer diagnosis, treatment, and control. Even lay population need increased cancer health literacy to be aware of cancer screening, prevention and control (Nielsen-Bohlman, Panzer & Kindig, 2004). This need is exemplified by the finding in this study where the participant describes his experience of being “caught off guard” from the cancer diagnosis. This participant attributed his age and overall health to be protective factors from cancer, which can be notion held by other people as well. Improving cancer health literacy through narratives can thus raise consciousness of people in terms of cancer knowledge. However it is important to note for future studies that personal narratives may not a well received form of communication for all cancer patients. This is demonstrated by one participant’s response who stated that she decided to “block out other peoples stories” so that they did not raise or lower her hopes. Another participant said she avoided personal blogs because they were “distasteful” and read credible websites. The findings also indicate that the experience of cancer may also be specific to the cancer. This is indicated by the participant who demonstrated the dramatic contrast in her initial positive experience with social support of breast cancer patients and later negative and lonely experience with parathyroid cancer. Another participant wanted to read a story with the “same type” of cancer. Thus narratives targeted as cancer patients should be tailored specifically to the type of cancer.

The findings of this study also demonstrate a need for more clarity about experimental cancer treatments. Cancer patients are willing to participate in experimental treatments because of their own diagnosis (Fallowfield, 1998). One participant described the positive health outcome of her aunt’s experimental treatments in Mexico which were not approved in the United States. However that participant gave no specific reason as to

why the treatments were not approved in the United States. Many treatments that can prove to be dangerous are not approved by the health care systems in the United States. Therefore narratives might be way through which correct information about experimental cancer treatments can be disseminated. Narratives with information about cancer treatments could be a possible way to recruit individuals for cancer clinical trials as well.

### **Limitations**

Even though this study provided important contributions to literature related to narratives and the cancer experience, it had some limitations. The first of these limitations is related to the thematic analysis approach of the study. Even though thematic analysis yields an outcome of commonalities and differences in the data, it is not necessary that the views of all the participants in a theme are exactly the same. The reader has to assume that all individuals within the thematic cluster mean the same thing. Also in the methodology of soliciting written narratives from participants, there is no opportunity to probe for detail. Thus, we ignore the deeper meaning of what the individual wanted to convey (Reissman, 2008). These deeper meanings and experiences could have been more thoroughly investigated with individual in-depth interviews.

Another limitation of this study is the limited sample of cancer patients selected for this study. This study intended to describe patients' experiences of cancer. There is a wide range of experiences that patients describe in terms of cancer, physically, emotionally, and psychosocially. Thus, having a larger sample size would have aided in representing a wider range of experiences in this description. Finally, due to the descriptive nature of this study, no generalizations were made across participants. Therefore the application of this study's results and implications is restricted to the

purpose of gaining a descriptive understanding of narratives, coping and the experience of cancer.

### **Concluding Thoughts**

In conclusion, this study has demonstrated that narratives can help individuals cope with their cancer diagnosis. This study also provides an insight into the unique nuances of the patient's experience of cancer. During the course of writing this thesis, I faced the cancer diagnosis of my own grandfather. The news was very disturbing for my family as well as for me. I was presented with a lived experience of the impact of a cancer diagnosis, and I did not like what I experienced. Even then, what I felt was only a fraction of what individuals who are actually diagnosed with cancer experience. It is important that we commemorate the strength of the millions of cancer patients who are faced with challenges that require courage and strength. In our attempts to advance knowledge about narratives in cancer and the experiences of cancer it is important that we respect each cancer patient's individual experience and learn from it. Even though this study provides evidence for the narratives helping patients cope with cancer, it is highly likely that narratives may not be suitable for all cancer patients. This ethical implication must be understood by researchers as well as practitioners. Cancer has already impacted the dignity and integrity of the patient, our endeavor must be restore their dignity and provide a quality of life that they deserve. This study helped me understand the stresses and complexities of the cancer experience for patients. In my future endeavors I hope to use what I have learned from this study to educate health care professionals about the importance of the illness experience from the patient's perspective. A lot of work needs to be done to restore compassion, love and empathy in health care. I believe that a society

can be judged on the basis of how it treats those who are diseased. I consider this thesis a platform for future studies aimed at creating deeper connections between patients and health care providers.



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