PATTERNS OF SYMPTOM DISTRESS DURING THE INITIAL TREATMENT PERIOD IN THREE CHILDREN WITH CANCER

by

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Nursing.

Chapel Hill

1999

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ABSTRACT
SHARRON LEE DOCHERTY: Patterns of Symptom Distress During the Initial Treatment Period in Three Children with Cancer (Under the direction of Professor Margarete Sandelowski.)

Childhood cancer treatment can be extremely aggressive and has been found to be more distressing and painful than the disease itself. This distress is a direct response to the symptoms caused by the side effects of treatment such as nausea, vomiting, retching, fatigue, anorexia, pain, stress, mood disturbances, and sleep alterations. Some children appear to adapt and cope well, whereas others are particularly susceptible to the physical intensity of the treatment symptoms and show physical, emotional, and behavioral manifestations of marked symptom distress. The ability to identify the symptom distress vulnerable child may be an important aspect of childhood cancer treatment and survival and an ultimate goal in prevention of long-term problems.

A longitudinal, case study design was used to examine the day-to-day symptom experience of 3 children, aged 7, 12, and 16 years, throughout the first 3 months of chemotherapeutic treatment to elucidate patterns of symptom distress that may emerge in response to the treatment. The symptom patterns tracked and studied were (a) pain; (b) stress; (c) sleep alterations; (d) fatigue; (e) nausea, vomiting, and retching; (f) anxiety; and (g) perception of symptom experience. The overall research question addressed was: What is the profile of symptomatic response in children produced as a result of the side effects of chemotherapeutic treatment for cancer?
Twice-daily data collection covered 3 months of the initial chemotherapeutic treatment protocol and included 3 classes of data collection techniques: self-report, biobehavioral, and interview. Visual inspection of the graphed data was used to examine the data for trends, patterns, and variability. The interview data was analyzed using content and narrative analysis techniques. Findings indicate that, for children, symptom distress is a constellatory mechanism and is not isolated to effects from individual symptoms. This distress may be expressed verbally, behaviorally, physiologically, and emotionally. The manner in which children express their distress may be dependent upon a multitude of factors including age, culture, and personality.
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In the 9 years that I practiced as a bedside pediatric oncology nurse, I became acutely aware of my colleagues’ ability to predict, very early in a child’s treatment initiation, how any particular child would fare in his or her struggle against cancer. While I am certain that a small proportion of their guesses was based upon data regarding the prognosis associated with different tumor and cell types, a larger proportion was related to something more basic that they were observing in the child. Indeed, two children could have the exact same prognostic indicators, and yet the nurses may guess that one would do very well and the other would struggle and have great difficulties. I have always been very interested in isolating the factors that nurses saw intuitively in children that allowed them to make such accurate guesses.

Eleven-year-old Sam was one of the last children for whom I cared prior to returning to school to pursue my doctorate. He was a child who the nurses would have guessed would have a lot of difficulty fighting his cancer. Michael did struggle gravely with his cancer, and more accurately, with his treatment. He seemed to develop every symptom that could possibly be developed while receiving his treatment. Over time, he became extremely sensitive to his symptoms and developed severe anxiety in response to them. Sam died on June 13, 1994, prior to completing treatment for his childhood cancer.
I visited with Sam’s mother before I left town for school in July 1994. As I was saying goodbye, she asked me what I was interested in studying while pursuing my doctorate. I told her that I was not entirely sure, but that it would have something to do with children and cancer. She reached out, held my hand, and said, “Sharron, find some answers for kids like Sam. Kids who just can’t stand the treatment.”

Patterns of Symptom Distress During the Initial Treatment Period

Over the past 25 years, there has been a dramatic change in the course of childhood cancers (Bleyer, 1990). Rather than being afflictions of rapid fatality, these diseases are now treatable conditions with variable outcomes (Hockenberry-Eaton, Diloria, & Kemp, 1995). This success has resulted largely from expansive multimodal therapy, which may include various combinations of surgery, radiation therapy, or multidrug chemotherapy. One of the most prominent success stories in the history of childhood cancers is that of leukemia. Alone it accounts for approximately 30% of cancers diagnosed in children under the age of 15 (American Cancer Society, 1993). The 5-year survival rate for children with acute lymphoblastic leukemia has risen from 10% in the 1960s to close to 90% in the 1990s (Ebb & Weinstein, 1997). Another example of the success in treating childhood cancer is the rise in survival rates for children with rhabdomyosarcoma from 20% in the 1960s to close to 60% in the 1990s (Stiller, 1997). This dramatic change in survival has resulted in an examination of the effects of treatment on the child and the family as the current survival rate will result in a population of approximately 200,000 survivors of childhood cancer by the year 2000 (Bleyer, 1990; Bradlyn et al., 1996).
Chemotherapy and Its Side Effects

Approximately 50 years ago, chemotherapy was first introduced into the treatment regimens for childhood cancers (Farber, Diamond, Mercer, Sylvester, & Wolff, 1948). Despite the improvements that resulted from other treatment modalities such as radiotherapy and surgery, history and research have shown that the introduction of cytotoxic drugs had the most dramatic effect on the survival rate (Riccardi, Larsorella, Nuti, & Mastrongelo, 1992). Today, while striking advances are being made daily in fields such as biochemistry, immunology, and molecular biology, which are helping us to understand the pathogenesis of childhood cancer, chemotherapy remains the number one factor responsible for the survival of children with cancer.

Despite the successes brought about by chemotherapy, a cost has accrued. Chemotherapy is known to be associated with major alterations in the physical, mental, and social worlds of the child during treatment and for an unlimited period of time following treatment (Deasy-Spinetta, Spinetta, & Oxman, 1988; Kashani & Hakami, 1982). These alterations result from symptoms brought about by treatment side effects, such as nausea and vomiting, diarrhea and constipation, fatigue, anorexia, cachexia, dysphagia, mucositis, stomatitis, xerostomia, alopecia, mood disturbances, and sleep alterations (Grunberg, 1993). The intensity, constellations, and patterning of occurrence of these symptoms, in combination with personal factors of the child and family, can result in a wide range of individualized, emotional responses to treatment, ranging from mild anxiety and distress to severe distress, which, in turn, can lead to possible interruption in or cessation of treatment and death.

In some cases, the distress caused by the side effects has been responsible for the cessation of treatment (Pinkerton & Hardy, 1997; Wilcox, Fetting, Nettesheim, & Abeloff).
1982). In a large survey in the United States, Nahata, Ford, and Ruyman (1992) reported that as many as 10% of pediatric and adult cancer patients refused further treatment because of the severe distress caused by nausea and vomiting. Researchers have reported that patients find the side effects so aversive and debilitating that they are regarded as worse than the cancer itself (Burish, Carey, Krozely, & Greco, 1987). Conversely, some clinicians have reported that the pharmacological advances made with new antiemetics and colony-stimulating factors have greatly decreased the distress that children experience (Rosoff, 1998). Investigators have not supported these reports.

Medical research has reached a point at which the intensity of the cytotoxic drugs needed to continue improving survival rates cannot be increased because of the toxicity and resulting distress brought on by the toxicities. In the new millennium, the problematic response to cytotoxic treatment may produce a leveling off of the childhood survival curves until research into supportive care of children undergoing treatment allows for the continued increases in the dosages and multidrug regimens now required.

Response of the Child to Symptoms

Curiously, while some children appear to be particularly susceptible to the physical intensity of the symptoms caused by chemotherapy treatment and show physical, emotional, and behavioral manifestations of marked distress, others appear to adapt to and cope well with the consequences of treatment. This latter group of children is able to display remarkable resilience to the multifaceted stress produced by the intense treatment for childhood cancer. This resilience is evidenced by their ability to maintain a normal lifestyle while learning to adapt to the symptoms produced by the treatment and by their ability to successfully complete their treatment programs. Yet other children have much more difficulty
coping with these symptoms and display physical, psychological, and behavioral manifestations that appear to accumulate across the treatment trajectory (Hockenberry-Eaton et al., 1994). The outward behavior of children undergoing treatment seems to fall into two categories: a battle with the cancer versus a battle with the treatment.

This differential response can be critical. Emotional and behavioral difficulties associated with aggressive chemotherapeutic treatment regimens have been shown to be related to adaptation to the disease, compliance with therapy, and eventual efficacy of the treatment in children with cancer (Dolgin, Katz, Zeltzer, & Landsverk, 1989; Hubert, Jay, Saltoun, & Hayes, 1988). The prolonged and intensive treatment for childhood cancer has been associated with increased risk for physical and behavioral disturbances (Drotar, 1981; Wallander, Varni, Babani, Banis, & Wilcox, 1988). Therefore, how a child with cancer adapts to and copes with the myriad symptoms brought about by cancer and its treatment can be a critical factor for not only quality of life during treatment but also the efficacy of the treatment itself and eventual survival of the child. The ability to identify the symptom-distress-vulnerable child could possibly be an important aspect of childhood cancer treatment and survival and an ultimate goal in prevention of long-term problems.

Although symptom distress instruments have been designed and used with adults and adolescents, little work has been done to explore and describe the meaning of symptom distress for children. Woodgate and McClements (1998) stated that, before developing an instrument to measure symptom distress in children with cancer, an understanding of how children experience the symptoms that emanate in response to cancer and its treatment is needed. They called for a study that used a meaning-centered approach that would capture the meaning and feelings that children assigned to the symptoms they experienced throughout the
illness trajectory. Studying children of different ages and in a variety of care settings using longitudinal designs would provide insights into developmental differences in children experiencing symptom distress over time. Understanding the process of symptom distress in children requires adult conceptualizations in conjunction with knowledge and scholarship in the field of child development and in the coping and stress experiences of children. Full adoption of the adult model is not appropriate because of the differing resources that children bring to an illness. Their ability to ask questions, form mental representations, and cognitively restructure an event are in part a product of developmental level. Viewing symptom distress as a multidimensional process occurring within the context of social systems is important.

Purpose of the Study

The purpose of this study was to explore the phenomenon of symptom distress from the perspective of school-aged children undergoing initial chemotherapeutic treatment for cancer. A longitudinal, case study approach, using qualitative and quantitative techniques, was used to examine the daily symptom experience of three children, throughout the first 3 months of chemotherapeutic treatment, to elucidate patterns of symptom distress that emerged in response to the treatment. The application of cytotoxic therapy brings side effects that produce a number of symptoms (Figure 1). My immediate goal was to develop a clearer understanding of the meaning symptoms have for children and the manner in which they express distress. Thus I describe the patterns of physical and behavioral experiences that resulted in response to the symptoms produced throughout the initial treatment period.
Figure 1. Conceptual model of treatment and symptom response.
Although symptom distress associated with chemotherapeutic treatment is a very unique and individual experience, I studied patterns of specific symptoms. The symptoms chosen for study were those that have been linked in the medical (Balis, Holcenberg, & Poplack, 1997), nursing (Rhodes, Watson, Johnson, Madsen, & Beck, 1987) and pharmacological (Riccardi et al., 1992) literature with the chemotherapeutic agents generally given in the treatment of childhood solid tumors. The symptom patterns that were tracked and studied in this proposal were (a) pain; (b) stress; (c) sleep alterations; (d) fatigue; (e) worry; (f) nausea, (g) vomiting, (h) retching, (i) mood alterations; and (j) perception of symptom experience. However, two of the data collection measures I used allowed me to identify other novel symptoms the children experienced. Describing the symptom experience of children being treated for cancer is central to understanding how supportive care may affect this experience and may assist in helping the child and family to navigate successfully the treatment period. This description also identifies important variables in the treatment trajectory, for future research and the testing of interventions with this population.

Research Question

The overall research question addressed in this study was: What is the profile of symptomatic response in children produced as a result of the side effects of cytotoxic treatment for a solid tumor and acute myeloblastic leukemia?

Sub-questions:

1. How do the individual biobehavioral and self-report symptom patterns (pain, fatigue, nausea and vomiting, stress, sleep alterations) contribute to the profile of symptom experience?
2. How do children describe and ascribe meaning to symptoms and their response to symptoms?

3. What is the confluence between the symptom patterns that emerge from the biobehavioral, self-report, and narrative accounts of the treatment experience?
CHAPTER TWO

REVIEW OF THE LITERATURE

Treatment for cancer in children is extremely aggressive and can be more distressing and painful than the disease itself (Balis et al., 1997; Gorfinkle & Redd, 1993). Although some children appear to adapt and cope well, others appear to be particularly susceptible to the physical intensity of the symptoms brought about by the treatment and show physical, emotional, and behavioral manifestations of marked distress. The underlying mechanism that may explain this differential response to the symptoms brought about by treatment may make the difference between success and failure of the cancer treatment.

In the past, nursing has focused on managing the symptoms caused by the side effects of disease treatment. Symptom management has entailed examining the occurrence, severity, frequency, and duration of individual symptoms (McDaniel & Rhodes, 1995). There is important literature in oncology on interventions aimed at single symptoms of disease, treatment, or both (Benoit et al., 1995; Bossert, Van Cleve, & Savedra, 1996; Miser, Dothage, Wesley, & Miser, 1987; Tyc, Mulhern, Jayawardene, & Fairclough, 1995; Tyc et al., 1993; Wright & Thomas, 1995; Zeltzer, LeBaron, Richie, & Reed, 1985), yet it is now evident from practice and research that focusing on the symptoms themselves has had limited success (Hinds, Quargnenti, & Wentz, 1992; Watson, Rhodes, & Germino, 1987). These observable and measurable reactions to treatment have received greater attention than the
individual's ability and inclinations to respond to, understand, and cope with their occurrence.

In adult populations, the emotional, behavioral, psychological, and physiological responses to the symptoms produced by disease treatment have been investigated and linked to the concept of symptom distress (Ehlke, 1988; Holmes, 1988; Holmes & Eburn, 1989; Kukull, McCorkle, & Driever, 1986; Lough, Lindsey, Shinn, & Stotts, 1987; McCorkle & Benoliel, 1983; McCorkle & Young, 1978; Rhodes & Watson, 1987; Young & Longman, 1983). Symptom distress has been defined as the physical or mental anguish or suffering that results from the experience of symptom occurrence, the perception of feeling states, or both (Rhodes & Watson, 1987). This concept has become central to the quality of life of a patient undergoing treatment. As an example of the influence of symptom distress, researchers studying adult lung cancer populations have found that levels of symptom distress recorded near time of diagnosis are predictive of survival (Degner & Sloan, 1995; Ganz, Lee, & Siau, 1991; Kaasa, Mastekaasa & Lund, 1989; Kukull et al., 1986).

The literature review that follows traces the development of the concept of symptom distress and highlights findings that relate to children undergoing treatment for cancer. I begin by examining the terms symptom, distress, and symptom distress, and summarize how these terms are used in the pediatric oncology literature. I then consider specific symptoms, including pain, stress, sleep alterations, fatigue, nausea and vomiting, anorexia, and mood alterations.

Symptoms

An examination of the origin and history of the word symptom may help to trace the transformation of its meaning. Usage of some form of the word can be dated back to the
16th-century Latin term *synthoma*, meaning to fall together or to happen (Skeat, 1910; Weekly, 1924). At this time, the term denoted a perceptible change in the body indicating disease. The Greeks altered the term to *sumptoma* to mean change, accident, mischance, to happen to, or fall upon (Onions, 1966; Skeat, 1910). A current definition of symptom is a perceptible change in the body or its functions, which indicates disease, or the sign of the existence of something (Webster’s Dictionary, 1992, p. 384). This definition demonstrates that there has been some variance in the term since its emergence. The loss of the early meaning of “to fall together” seems to have made an impact on the manner in which we examine responses to symptoms by taking that response apart and looking at each facet of the response in isolation. The patterning or constellation of symptoms and the effect of this constellation on an individual seem to have been lost.

Symptom now denotes a departure from normal functioning and is usually described as unusual or unpleasant sensation or sensations (Burman, 1996; Giardino & Wolf, 1993; Wenger, 1993). Symptoms are often perceived as signaling an illness or disease. The early definition included the notion of symptom as a sign of the existence of disease (Onions, 1966). Together, signs and symptoms were taken as an indication, warning, or symbol of an unforeseen phenomenon (Webster’s Dictionary, 1992, p. 574). However, the majority of writers in this century used the terms signs and symptoms to refer to different facets of response. Sign refers to an observable, objective indicator of disease, and symptom to a subjective, perceptual, not observable state.

The biomedical profession has a long history of relying on patients’ reports of symptoms. Definitions from this field include any perceptible change in the body or its functions that indicate disease or the kind or phases of disease (Taber’s, 1977). This is quite
different from the definitions used by other biobehavioral professions in which the expression of a symptom does not necessarily denote disease. For example, medical anthropologists view symptoms as representative of not a disease process alone but also the meanings the illness has for the involved person (Good & Delvecchio, 1980; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978). This definition highlights the large cultural component of symptoms. Wenger (1993) proposed that because symptoms are perceived by humans and are expressed in the language and behavior of particular cultures, beliefs, and values, symptoms have cultural meaning. Several researchers have affirmed Wenger’s (1993) assumption that as humans experience pain or other symptoms, they interpret them and react in ways that fit their cultural norms. These studies have focused on the expression of specific symptoms such as pain, diarrhea, or depression (Calvillo & Flakerud, 1991; Kirkpatrick & Cobb, 1990; Kosko & Flakerud, 1986; Rosenbaum, 1989).

An important trend in usage of symptom has been to apply the term to the response to the side effects of treatment for disease. Investigators have studied the occurrence, severity, frequency, and duration of specific symptoms of the treatment of childhood cancer. These specific symptoms are presented later. Thus, although the term symptom has been defined and interpreted in a variety of ways, the common meaning is that it is a response to disease, the treatment of disease, or both.

Distress

Distress has been defined as mental or physical pain imposed upon a person and implied a notion of suffering (Webster’s Dictionary, 1992, p. 119). Distress was linked very early to disease and to the treatment of disease. A wide variety of stressors ranging from the psychological to the physiological have been documented as impinging on a person with a
disease or who is undergoing treatment for that disease. Distress has been shown to be experienced as a range of responses such as anxiety, anger, apprehension, immobility, vulnerability, and dependency (Rhodes & Watson, 1987).

A number of researchers have studied children's adjustment to the distress of chronic illness and its subsequent treatment (Neville, 1996). These researchers have focused on how children manifest and adjust to the distress forced upon them by illness and treatment (Perrin & MacLean, 1988). In a study of the effects of hospitalization on children, Mabe, Treiber, and Riley (1991) found that children's distress response manifested itself in depressive and anxious symptoms, which were positively related to duration of physical symptoms and parental distress. Other researchers have investigated the effect of procedural distress on children's response to future medical intervention. This is an important area of study in childhood cancer as children find procedural and investigational aspects of cancer treatment to be worse than the disease itself (Ross, 1989; Weekes & Savedra, 1988; Weekes, Kagan, James & Seboni, 1993; Zeltzer, Kellerman, Ellenberg, & Dash, 1980). Results have indicated that children with previous negative medical experiences demonstrated more behavioral distress during a throat culture examination than did children with previous positive or neutral medical experiences (Dahlquist et al., 1986). Several researchers have examined the distress of children with cancer undergoing bone marrow aspirations or lumbar punctures (Jay, Ozolins, Elliot, & Caldwell, 1983; Katz, Kellerman, & Siegel, 1980; Bradlyn, Harris, Ritchey, & Zaboy, 1993). In many of these studies of procedural distress, researchers have sought to quantify the amount of distress experienced. Distress that encompasses pain, anxiety, or other behavioral manifestations has typically been measured using behavioral rating scales, making identification of the particular cause of the distress difficult.
Specific side effects of treatment have been studied as a stressor. Kerry (1990) demonstrated the centrality of the side effects of treatment to children with cancer in a study of adolescent survivors of cancer. These children reported that they would refuse treatment if their cancer were to recur because of the distressing side effects of the treatments. Those side effects that frequently alter the child’s physical appearance, such as hair loss and changes in body weight, have been found to cause children to become highly distressed (Chekryn, Degan, & Reid, 1987). Researchers studying specific side effects have used instruments to examine distress that were originally designed as measures of psychological distress in healthy children (e.g., Spielberger STAIC, Harter Self-Perception Profile for Children). These tools may not be sensitive enough to capture the possible distress children experience when responding to symptoms of cancer and its treatment or the meanings the children ascribe to their experiences (Woodgate & McClement, 1998).

Symptom Distress

Symptom distress is distinguished from symptoms of distress in that the latter are the consequence of a more global stress response. Symptom distress is seen to have a more specific stressor (Rhodes & Watson, 1987). Engel (1960) appears to have been the first scholar to link the terms symptom and distress and to advocate the need to relieve the patient of the distress brought about by a symptom. Initial attempts at measuring a concept similar to symptom distress were undertaken by Hinton (1963) in his study of the physical and mental distress of patients dying of cancer. Hinton (1963) used the term physical distress, which he defined as any untoward effect that distressed the patient enough to warrant treatment directed toward its relief. He isolated symptoms of pain, dyspnea, nausea, vomiting, and fatigue as causes of this type of distress.
Definitions of symptom distress have included the physical or mental anguish or suffering that results from the experience of symptom occurrence, the perception of feeling states, or both (Rhodes & Watson, 1987). The meaning that a symptom has to an individual has been isolated as an important component of symptom distress, in that the same symptom can bring about vastly differing levels of symptom distress in different individuals (Larson, Viele, Coleman, Dibble, & Cebulski, 1993). Thus symptom distress can be seen as a critical element in how people cope with their illness. This meaning is based on individual factors such as culture (Wenger, 1993) and past experience with symptoms (Giardino & Wolf, 1993). Tishelman, Taube, and Sachs (1991) found symptom distress to be a reflection of both sickness and illness perceptions, as opposed to the disease process alone. They argued that further study using more flexible research methods aimed at gaining deeper understanding prior to testing hypotheses is needed because of the complex nature of the phenomenon. Mechanic (1980) advanced the notion that symptom reporting reflected a pattern of illness behavior influenced by the actual occurrence of illness, developmental experiences, and sense of well-being.

Conceptualizations of symptom distress from the adult literature can be somewhat confusing because of the lack of explicit conceptual models to understand the concept and its related constructs and relationships. Rhodes and Watson (1987) attempted to provide some structure to the conceptualization of symptom distress by linking it to general systems theory and self-regulating theory. Many of the empirical studies in which the concept is used have been guided by a cognitive appraisal model of stress and coping (Lazarus & Fokkman, 1984), in which an individual’s appraisal or evaluation of the personal meaning of the situation (primary appraisal) and his/her resources to deal with it (secondary appraisal) are postulated.
to mediate the effects of other factors. Currently, the concept of symptom distress, once operationalized, is used more often to indicate distress brought about by the treatment of disease or by the side effects of treatment.

In conclusion, without clear conceptualizations, terms such as signs, symptoms, symptom distress, symptom management, and the more recent symptom experience are often used interchangeably. Signs are seen as more definitive, measurable, and separate from patient impressions. The term symptom management introduced by the University of California, San Francisco, School of Nursing, Symptom Management Faculty Group (1994) was intended to encompass three dimensions: the symptom experience, symptom management strategies, and symptom outcomes to ensure a comprehensive approach to symptom management challenges. McDaniel and Rhodes’ (1995) used the term symptom experience to represent the total symptom experience, which included the occurrence of a symptom, including frequency, severity and duration, in addition to the distress that it caused (Rhodes, McDaniel & Hanson, Markway & Johnson, 1994).

Measurement and Research Issues

Over the past 3 decades, the concept of symptom distress has been operationalized in several scales designed for use with a variety of chronically ill populations. The most commonly used measure of symptom distress is the Symptom Distress Scale (SDS) (McCorkle & Young, 1978), which was originally designed to measure the degree of discomfort associated with 10 symptoms commonly experienced by patients during treatment for cancer. The SDS is a Likert scale, with higher scores indicating more distress. The SDS has been used in more than 25 studies on populations of men, women, and adolescents with...
chronic illnesses such as cancer, heart disease, and pulmonary disease. The SDS has also been used with organ transplant candidates, post-polio survivors, and HIV positive men.

Another symptom distress measure is the Memorial Symptom Assessment Scale (MSAS). This is a comprehensive Likert-type measure that records prevalence of a full range of both physical and psychological symptoms according to severity, frequency, and distress (Portenoy, Thaler et al., 1994). The MSAS appears to have several benefits over the SDS in that it assesses psychological symptoms as well as physical symptoms. The MSAS has three subscales, which can then be combined to get a total overall symptom distress score. This separate analysis of intensity, frequency, and distress with each symptom has been found useful.

Other measures of symptom distress include the Heart Transplant Symptom Checklist (Grady, Jalowiec, Grusk, White, & Williams, 1992), the General Symptom Distress Scale (Lalonde, 1987), the HIV Symptom Distress Scale (Lovejoy, Paul, Freeman, & Christiansen, 1991), the Rotterdam Symptom Checklist (de Haes, Van Knippenberg, & Neijt, 1990), and the Symptom Rating Test (Kellner & Sheffield, 1973). These measures appear to be quite similar with some being more applicable to specific illness groups and the psychological aspects of the illness in general.

One common weakness in all of these ordinal measures is that there is no way in which to assign weights or importance to various symptoms based upon the importance of each symptom to the patient (Degner & Sloan, 1995). This weakness is of particular importance when studying a symptom in which the individual’s unique background and experience are important contributors to the distress experienced and would help to identify the meaning of the symptom to the individual. Moreover, the unidimensional nature of these
scales does not allow for the study of the effect of the patterning of symptoms or constellatory mechanisms that occur during treatment for many chronic illnesses. One study approach that allowed for a more diverse view was the use of an interview methodology (Tishelman et al. 1991). In this study, interviews were found to be critical in understanding symptom distress with an older population and much of the data obtained by interview contradicted data obtained using the SDS.

The measures described above have permitted the widespread study of a limited conceptualization of symptom distress. Symptom distress has been examined as predictor, covariate, outcome, and mediating variable. Table 1 lists published studies that have used symptom distress as a variable. In general, the strength of the concept is as a predictor and explanation for many patient outcomes and concerns. While symptom distress scores with several populations were low (Denger & Sloan, 1995; Ehlke, 1988; Lovejoy et al., 1991; McCorkle & Benoliel, 1983), the cumulative effect of symptoms on distress was often the most important predictor of variables such as emotional distress (Love et al., 1989). The prevalence of a symptom often exceeded the proportion of patients who described it as distressing.

Symptom Distress and Children

A study of the complex response to the symptoms that arise out of treatment for childhood cancer is not available. Some researchers have examined the concept with adolescents (Ellis, 1991; Enskar, Golsater, & Hamrin, 1997; Hinds et al., 1992; Zeltzer, 1993). In addition, a number of studies have addressed the individual and specific symptoms that are the focus for this study.
### Table 1

**Summary of Symptom Distress Literature**

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Symptom Distress as Antecedent</th>
<th>Symptom Distress as Covariate</th>
<th>Symptom Distress as Outcome</th>
<th>Symptom Distress as Mediator or as Mediated by</th>
</tr>
</thead>
</table>
| Age           | - strong positive association (43)  
                - positive association with N/V & mood (16)  
                - weak negative association (1)  
                - negative association with nausea & appetite (42,43)  
                - no association (39,10) |                                | on interview: participants reported increased symptom distress in older people (42) |                                |
| Sex           |                                |                                | - higher levels in women (43,1,24)  
                - higher levels in men (22)  
                - no difference between groups (10,39) |                                |
<p>| Education     | - no association (10)          |                                |                                |                                |
| Survival      | - direct negative prediction with lung cancer participants (2,3,4,5) | - negative association (1) |                                |                                |</p>
<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Symptom Distress as Antecedent</th>
<th>Symptom Distress as Covariate</th>
<th>Symptom Distress as Outcome</th>
<th>Symptom Distress as Mediator or as Mediated by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>- direct positive prediction of lung cancer participants out of a sample of heterogeneous cancer diagnoses (1)</td>
<td></td>
<td>- no differences by tumor type (39)</td>
<td>- lung cancer participants had higher scores than MI participants (6, 11, 26)</td>
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<td>- lung cancer participants had higher reports of pain, nausea than COPD/MI/CVA (22)</td>
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<tr>
<td>Length of Illness</td>
<td>- negative association for symptoms of pain, nausea, bowel patterns (37)</td>
<td>- no association with cancer disease stage (43, 15, 14, 23, 9)</td>
<td>- recurrent cancer group had higher scores than initial tx. group (31)</td>
<td>- positive association with cancer disease stage &amp; recurrence (31, 1)</td>
</tr>
<tr>
<td>Informant</td>
<td></td>
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<td>- no difference between women &amp; their husbands (33)</td>
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<td></td>
<td></td>
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<td>- nurses report higher scores than their clients (18)</td>
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<td></td>
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<td></td>
<td></td>
<td>- nurses report lower levels than their clients (23)</td>
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<tr>
<td>Location of Care</td>
<td></td>
<td></td>
<td></td>
<td>- no difference between office care &amp; home care at T1 but office care group elevated earlier at T2 (27)</td>
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<td>- home care had higher levels at baseline than no home care group (29)</td>
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<tr>
<td>Variable Name</td>
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<tr>
<td>Treatment Modality</td>
<td></td>
<td></td>
<td></td>
<td>- chemotherapy group had higher total score than radiation group (16)</td>
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<tr>
<td>Uncertainty</td>
<td></td>
<td>- no association (10)</td>
<td></td>
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<tr>
<td>Appraisal of Situation (Sense of Meaning)</td>
<td>- direct positive prediction (31)</td>
<td>- pain predicted acknowledged awareness (11)</td>
<td>- positive association for lung cancer clients but not for MI clients (11)</td>
<td>- appraisal mediated or reduced direct effects of symptom distress (35,31)</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>- direct negative prediction (12,8,39)</td>
<td>- negative association (36,32,12,24,13)</td>
<td>- group with low quality of life had higher symptom distress scores (17)</td>
<td></td>
</tr>
<tr>
<td>Social Functioning</td>
<td>- direct positive prediction with social dependency (6)</td>
<td>- negative association with social interaction &amp; relationship with caregivers (7)</td>
<td></td>
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<tr>
<td>Emotional-cognitive Distress (Mood)</td>
<td>- direct positive prediction (6,20,21,26,31,39)</td>
<td>- strong positive association with depression (20)</td>
<td>- levels of depression predicted symptom distress scores (20)</td>
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<td></td>
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<td>- very strong negative association with mood (suggested collinearity) (35,25)</td>
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<td>- no association with well-being (9)</td>
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<tr>
<td>Adjustment to Illness</td>
<td>- direct positive prediction (33)</td>
<td>- negative association (33,41)</td>
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<tr>
<td>Anticipatory Nausea &amp; Vomiting</td>
<td>- direct positive prediction (38)</td>
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<tr>
<td>Variable Name</td>
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<tr>
<td>Self-care Burden</td>
<td>- direct positive prediction</td>
<td>- positive association with impact on ADL (35,17)</td>
<td></td>
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<tr>
<td>Internal Locus of Control</td>
<td>- negative association (7,19)</td>
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<tr>
<td>Coping Resources</td>
<td>- negative association (19)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Stress</td>
<td>- high positive association (43)</td>
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</table>


**Pain Perception in Children with Cancer**

Researchers studying childhood cancer have provided evidence that pain is a common symptom. The incidence of pain in children/adolescents has been documented by chart review, ethnographies, and self-report behavioral assessment (Bossert et al., 1996). While these studies have documented the existence of pain in children with cancer, Sutters and Miaskowski (1992) called for the need to identify pain trajectories for this population that can direct and guide clinical practice.

Researchers have documented that 60% to 80% of children with cancer report some type of pain (Cornaglia, Massimo, Haupt, 1988; Sutter & Miaskowski, 1992). Pain in children with a solid tumor can result from the direct effects of the cancer, from treatment-related side effects, or it can be associated with invasive procedures (Rostad & Moore, 1997). Pain from the direct effects of the malignancy can arise for a number of reasons, such as displacement and nerve compression.

Several researchers documented the presence of pain in children with cancer. Miser, McCalla, Dothage, Wesley, and Miser (1987b) found that pain was a presenting symptom in 72 of 92 newly diagnosed pediatric cancer patients. This sample of children were followed throughout cancer treatment until they were pain free. Pain persisted for 9 months, a median of 74 days, or until they died (Miser et al., 1987b). A chart review conducted over a 10-year period found that, although 68% of children reported pain, 57% reported having pain of moderate to severe intensity (Cornaglia, Massimo, & Haupt, 1988).

Many of the treatment-related side effects of cancer treatment are accompanied by pain. The most dramatic are the oral complications of mucositis, stomatitis, and xerostomia (Dose, 1995). Mucositis is the generalized inflammation of mucous membranes.
Chemotherapy interferes with cell growth, maturation, and replication, directly causing changes in the oral mucosa. Reduction in renewal of the basal cells leads to atrophic changes and breakdown of collagen. Erythema and sensitivity of the oral mucosa results from these changes and may progress to superficial epithelial sloughing, intense redness of the tissues, and ulceration (Dose, 1995). Mucositis usually occurs approximately 5 to 7 days after the administration of chemotherapy, and in myelosuppressed children can resolve fairly quickly if prompt mouth care treatment is initiated and the neutrophil count begins to rise. Buccal, labial, and soft palate mucosa are the sites most often involved (Lilley, 1990). The surface of the tongue and floor of the mouth are also affected. If oral mucositis continues untreated, hemorrhagic ulcerations may develop. Dose (1995) reported that 39% of adults and 90% of children will develop mild to severe stomatitis after chemotherapy, attributing the higher percentage in children to the higher rate of mitotic activity in their oral mucosa. Less than effective mouth care regimens may also be responsible for the higher percentage rate.

Pain brought about from the invasive procedures that accompany childhood cancer treatment can be quite dramatic (Bossert et al., 1996). Jacobsen and colleagues (1990) dramatically illustrated the potential for painful episodes in children undergoing cancer treatment. In studying 3- to 10-year-old children undergoing treatment for acute lymphoblastic leukemia, researchers found they had undergone an average of 93 venipunctures, with a range from 2 to 300, in the previous 32 months. Findings from these studies revealed a relationship between procedural pain and age and between quantity and type of distress-related behavior (Bradlyn et al., 1993; Jay et al., 1983; Katz et al., 1980). Children younger than 7 years old exhibited more expressive, action-oriented behaviors, whereas children older than 7 years showed more control over their physical and emotional...
reactions to procedure-related pain. These studies have suggested some qualitative and quantitative differences in distress-related behaviors for various age groups of children. Younger children do not necessarily experience more distress than older children but manifest more intense overt behavior in comparison to older children (Woodgate & Kristjanson, 1995, 1996).

Stress in Children with Cancer

Stress or distress has long been linked with chronic diseases in childhood. Researchers have examined the effects of childhood cancer treatment on indicators of stress by studying its effects on the emotional, social, behavioral, and physiological functioning of children undergoing treatment. Some of the more specific constructs that have been operationalized through various scales and used as indicators of emotional stress are mood, depression, and anxiety.

One faction of researchers has concluded that children undergoing cancer treatment do not differ on indicators of generalized stress when compared to their healthy peers (Canning, Canning, & Boyce, 1992; Kaplan, Busner, Weinhold, & Lenon, 1987; Noll, 1999; Olson, Boyle, Evans, & Zug, 1993; Worchel et al., 1988) or from children with other chronic illnesses (Siefert, Wittmann, Farquar, & Talsma, 1992). However scholars in the field of pediatric chronic illness have cautioned that many of the findings from these studies can be partially attributed to methodological limitations in design and instrumentation (Hinds, 1999; Last, & Grootenhuis, 1998; Van Dongen-Melman, Pruyn, De Groot, Koot, Hahlen, & Verhulst, 1995) The majority of these studies are cross-sectional, which represent one slice in time during a child’s illness. This slice may not be predictive of the child’s long-term

Several researchers have addressed the effects of cancer treatment on physiological indicators of stress. These stress reactions can be brought on by the painful episodes of illness and treatment, which can induce a physiological reaction of humoral, immune, and neural outflows leading to important alterations in metabolism and major organ system functions (Anand, 1993). In addition, there is growing support that the psychological stress of illness and treatment has a strong influence on cellular and humoral immune functions (Ader, Felten, & Cohen, 1991; Anand, 1993; Cohen, Tyrrell, & Smith, 1991). Physiologic stress has been measured using biochemical measures that reflect the activity of the endocrine system (Baum, Grunberg, & Singer, 1982). These include epinephrine, norepinephrine, and cortisol.

The physiologic response to a stressor is a protective device that maintains homeostasis and is initiated in the hypothalamus (McCance & Heuther, 1996). Corticotropin-releasing factor (CRF) is produced by the hypothalamus and once released stimulates the production of adrenocorticotrophin hormone (ACTH). ACTH is the main regulator of cortisol secretion and adrenocortical growth. Three factors regulate the secretion of ACTH: (a) high levels of cortisol, which suppress CRF and ACTH; (b) diurnal rhythms; and (c) high stress, which increases ACTH secretion, leading to increased cortisol levels (McCance & Heuther, 1996).

The cortisol response of the HPA axis to stressors decreases rapidly over time and is associated with feelings of discomfort and anxiety. Cortisol has many metabolic, anti-inflammatory, and growth-suppressing effects that influence awareness levels and sleep..
patterns (Born, deKloet, Wenz, Kern, & Fehm, 1991) and thus are particularly significant to the child with cancer.

Only a few investigators have assessed cortisol response to stress in chronically ill children and have documented hormonal response to hospitalization and related procedures. The findings are inconsistent in their methodologies. Barnes, Kenney, Call, and Reinhart (1972) and Knight and colleagues (1979) measured cortisol excretion in hospitalized children and attempted to relate it to behavioral and psychological profiles and obtained inconsistent results. A group of Swedish scholars (Edwinson, Arnbjornsson, & Ekman, 1988) reported the response of 24 school-aged children to an emergency appendectomy and found that children in both the informational prepared and unprepared groups had increases in cortisol levels. However, the cortisol levels showed different rates of increase between the two groups.

Despite the lack of studies that relate chronic illness and physiological stress markers in school-aged children, researchers in other settings have documented this important hormonal response. Scholars have examined and found cortisol levels to be related to behavioral states in early infancy (Tennes & Carter, 1973), separation and stranger anxiety in 1 year olds (Tennes, Downey, & Vernadakis, 1977), and test anxiety in school-aged children on test day (Tennes & Kreye, 1985). Kagan, Reznick, and Snidman (1987) found children who were cautious and shy had elevated cortisol responses to novelty, whereas another group of fearless and outgoing children showed small changes in physiologic stress responses. Studies of children's responses to stressful medical procedures have included several studies of circumcision and immunization in newborns and infants (Gunnar, Fisch, Korsvik, & Donhowe, 1981; Gunnar, Malone, Vance, & Fisch, 1985; Lewis & Thomas, 1990; Talbert, Kraybill, & Potter, 1976).
Some investigators have attempted to study whether children habituate and thus become less distressed to repeated invasive procedures. A study of cancer treatment procedures found no significant decrease in stress levels as measured by cortisol when controls were placed for age and type of venous access device (Jacobsen et al., 1990). Conversely, Gunnar, Connors, and Isensee (1989) found rapid habituation of the adrenocortical response to repeated stimulation when infants were given discharge examinations that were designed to heighten arousal over several days.

In summary, salivary cortisol has not been used as a proxy measure of physiological stress in children with cancer. However, researchers studying other groups of children undergoing life stress have found support for the use of this biochemical marker as an indicator of physiological stress. Importantly, little evidence links this physiological stress marker with behavioral indicators of distress, thus indicating that they may be measuring differing factors of the stress response.

**Sleep Alterations and Fatigue in Children with Cancer**

Theories regarding the purpose of sleep have been summarized by Hobson (1989) with the most popular being the restorative theory. This theory proposes that sleep promotes physiological processes that rejuvenate the body and the mind. Sleep is believed to both build and repair tissue (Adam & Oswald, 1983, 1984). Several adult studies provide evidence of tissue renewal associated with release of growth hormone during deep sleep (Chuman, 1983; Lee & Stots, 1990). Several other theories are available, however empirical data supporting any of them is limited. Despite its centrality to life processes, many things can interfere with sleep. Sleep is a highly variable state and is very easily disturbed. Internal factors such as stress, anxiety, depression, pain, and discomfort have been noted to influence sleep (Shelden,
Spire, & Levy, 1992). Multiple external stimuli (e.g., noise, light, activity) can exert strong and negative influences that result in dysfunctional sleep. Prolonged total sleep deprivation is incompatible with life, and lesser sleep loss causes physiologic changes not conducive to health (Hobson, 1989).

Sleep habits change dramatically during the early developmental years. Infants sleep approximately 16 to 17 hr a day. Over the next few months, they begin to sleep through the night. Eventually, the total sleep time decreases, and by 5 years of age a child needs 10 to 12 hr of sleep a night (Hobson, 1989). Lee and Stots (1990) suggested that growth hormone was critical to the healing process in children and that 70% of the 24-hr total secretion of this hormone occurs during sleep. The impact of poor sleep quality on the health of children may be linked to difficulty in coping with stress. Studies have shown that children who have more sleep disturbances also experience a greater number of stressors (Kataria, Swanson, & Trevathan, 1987).

Restful sleep is a state in which the mind and body can conserve energy by reducing metabolic requirements, restore depleted resources lost in the wakeful hours, and promote learning and memory (Sheldon, Spire, & Levy, 1992; Spenceley, 1993). When children’s sleep patterns are disturbed by painful procedures, they do not experience restful sleep. Furthermore, if pain and lack of sleep are continuous, other more global/functional behaviors are affected (Sheldon, Spire, & Levy, 1992).

In infants, changes in sleep patterns have been found to occur after noxious procedures. Scholars have found that infants circumcised without anesthesia experienced prolonged periods of nonrapid eye movement (Emde, Harmon, Metcalf, Koenig, & Wagonfeld, 1971), increased wakefulness (Anders & Chalemian, 1974, Brackbill, 1975),
increased irritability, and less ability to interact (Dixon, Snyder, Holve, & Bromberger, 1984). Although the link between stress and sleep has gone unexamined in the school-aged child, researchers who examined the number of negative life events experienced by children and how these events related to sleep and fatigue found high levels of stress related to more sleeping and waking problems than in children with less stress (Tobia, Wolfson, & Gallagher, 1995). Varni and colleagues (1996), in a study of children with known musculoskeletal pain associated with rheumatologic diseases, found that a sleeping child is not necessarily indicative of a stress-free child. Children in this study used sleep as a way of coping with the pain, and they used sleep as a mechanism of escaping from the pain.

A symptom intricately linked to sleep alterations is fatigue. In studies of adults with cancer, fatigue is one of the most universally experienced side effects of chemotherapy, with estimates ranging from 80% to 90% (Irvine, Vincent, Graydon, Bubela, & Thompson, 1994). In a preliminary study to identify the components of fatigue in populations of children with cancer, Hinds and colleagues (Hinds et al., 1999; Hockenberry-Eaton et al., 1998) used a focus group design with parents, staff, and children. They concluded that, conceptually, fatigue is a state of diminished to complete loss of energy or will that is influenced by environmental, biochemical, personal, cultural, and treatment-related factors. They added that fatigue may be acute, episodic, or chronic, and can be accompanied by a changing emotional or mental state. No studies are available that evaluate fatigue or sleep alterations in children with cancer.

**Nausea, Vomiting, and Anorexia in Children with Cancer**

Researchers have noted that nausea and vomiting are the most commonly reported side effects of cancer treatment and, in conjunction with fever and pain, are the symptoms
found most distressing for the child (Rostad & Moore, 1997). The majority of research regarding symptom occurrence and distress related to treatment of children with cancer has focused on nausea and vomiting. Nausea is defined as a subjective experience of distress centered in the back of the throat, the epigastrium, and gut, and often culminates in vomiting (Hogan, 1990). Studies have documented that 30% to more than 75% of adult cancer patients receiving chemotherapy experience vomiting in relation to the feeling of nausea (Needleman, 1987; Sallan & Cronin, 1985).

Vomiting is defined as the oral expulsion of the gastric contents that occurs as a result of positive changes in the intrathoracic pressure (Hogan, 1990). The emetic center is composed of both the vomiting center and the chemoreceptor trigger zone and receives input from a variety of peripheral and central afferent sources. The irritation to the chemoreceptor trigger zone is most frequently identified as the primary cause of chemotherapy induced nausea and vomiting (Borison, 1986). While nausea and vomiting are known to be linked to a pharmacological origin, the contribution of psychological and physiological factors is increasingly being recognized (Jacobsen et al., 1988).

One important area of study that has emerged from a focus on nausea and vomiting, and that has implications that may be generalized to other areas of symptom response, is anticipatory nausea and vomiting. Anticipatory nausea and vomiting are a learned conditioned response stimulated by something that occurs in association with the true stimulant, in this case chemotherapy. Through repeated pairings with chemotherapy and its after effects, previously neutral stimuli (e.g., the sights, sounds, and odors of the treatment setting) acquire nausea and emesis eliciting properties (Redd & Hendler, 1984). Anticipatory
nausea and vomiting develop in approximately 33% of adult patients and usually occur after the third or fourth cycles of chemotherapy (Cotanch & Strum, 1987).

Several groups of researchers have examined the impact of nausea and vomiting on the child undergoing cancer treatment. Documentation of the emotional effects includes feelings of anxiety, hopelessness, and loss of control (Keller, 1995). Zeltzer and colleagues (Zeltzer, LeBaron, Ritchie, & Reed, 1988; Zeltzer Dolgin, LeBaron, & LeBaron, 1991; LeBaron, Zeltzer, LeBaron, Scott, & Zeltzer, 1988) explored whether children could use a self-report rating scale to quantify nausea and vomiting in a series of vignettes. They asked the child to rate the amount of time they thought the child in the vignettes spent having nausea and vomiting as well as the extent to which the child was bothered by the symptoms. Healthy children as well as children with cancer were able to use the rating scale and no significant differences were found between the children’s and adults’ ratings. This finding was supported by Tyc and colleagues (Tyc et al., 1995; Tyc et al., 1993). In the Zeltzer study, vomiting was consistently rated as occurring for longer duration and producing more bother than nausea. The researchers concluded that highly distressing symptoms may be perceived as occurring for longer duration than less distressing symptoms (Zetzer et al., 1988).

In children already at risk for nutritional compromise, nausea and vomiting can promote other deleterious complications such as metabolic imbalances, dehydration, anorexia, stomatitis, and depression (Hanigan & Walter, 1992). Nausea and vomiting may cause weight loss, nutritional deficits, electrolyte imbalances, weakness, and lethargy in children (Hockenberry-Eaton & Benner, 1990). Chemotherapy is documented as a main contributor to treatment-related nutritional compromise in patients with cancer (Eilers,
Berger, & Petersen, 1985). Learned food aversions induced by the association of food with the unpleasant side effects of the treatment frequently occur (Bernstein, 1982).

**Mood Alterations in Children with Cancer**

Several researchers have looked at alterations in mood of children with cancer and have found that they are not significantly more depressed than other populations of children. Worchel and associates (Worchel, Copeland, & Barker, 1987; Worchel, et al., 1988) studied children during treatment, they compared them with children with psychiatric diagnoses and with healthy school children, and found that the children with psychiatric diagnoses had higher levels of depressive symptoms than did the children with cancer or the healthy children. The healthy children had higher levels of depression than the children with cancer. Mulhern, Fairclough, Smith, and Douglas (1992), in a study of children undergoing treatment for cancer, found that less than 10% had clinically significant scores on depression scales. These studies indicate that symptoms of depression are infrequent in children undergoing treatment for cancer when measured by self-report.

**Conclusions**

The dramatic change in the survival of children with cancer has brought about a reexamination of the effects of treatment on the child. While a few groups of researchers have begun to delve into this important area, there is still a paucity of literature that examines the day-to-day treatment experience of this population of children. Limitations in our current research methodologies, including instrumentation and access to the world of children, have been the major contributors to this lack of study.
CHAPTER THREE

METHODOLOGY

A longitudinal (i.e., time-series), case-study design (Kratochwill, 1978; Stake, 1995) was used to capture the symptom experience of three children undergoing initial chemotherapeutic treatment for cancer. The case study is a design strategy that is not located in any one methodological domain. The case study may contain qualitative or quantitative techniques, or both, but the orientation is always toward understanding the particulars of one unit, in this case one child, around a specific constellation of events (Sandelowski, 1996; Stake, 1995; Stoecker, 1991). The continuous assessment of data and the search for trends over multiple sources, as well as the focus on the singular and unique are hallmarks of longitudinal, case study investigations (Kazdin, 1982; Stoecker, 1991).

Symptom distress has been conceptualized as a transitional state that emerges or develops over time. Accordingly, the longitudinal design, with its emphasis on repeated measures across time, is an appropriate design to capture this dynamic state (Bergman, Eklund & Magnusson, 1989; Kelly & McGrath, 1988; Lentz, 1989). A time-series design, as Seed (1995) described it, enables the capture of a moving picture, which may allow patterns of symptom distress to emerge. This design uses individual variability data to describe, model, and explain a response (Lentz, 1989).
Participants

The case in this study was a child, between the ages of 7 and 16 years, newly diagnosed, with a solid tumor who was undergoing a standardized chemotherapeutic treatment protocol. Critical case sampling (Patton, 1990) was used to select 3 such cases. Critical case sampling is a purposeful sampling technique which involves choosing cases which have the highest potential to illustrate the study phenomenon quite dramatically. In order to profile the symptom experience of the child being treated for a solid tumor, it was necessary to choose the cases which would provide the most information regarding the symptom experience.

I made three decisions to identify and thus define the critical case for this study. The first decision was to study the effects of chemotherapeutic treatment on a child’s symptom experience. Whereas other childhood cancer treatment modalities, such as radiation, surgery, and bone marrow transplantation, produce similar side effects and thus potentially similar responses to treatment, chemotherapy used alone was a feasible starting point, as most treatment protocols include at least chemotherapy and other modalities may produce side effects or co-morbidities that may obscure the appearance of the symptom experience.

In an examination of childhood cancers that are treated almost exclusively with chemotherapy, the leukemias stand out (Pinkerton & Hardy, 1997). However, treatment for childhood leukemia has progressed so effectively that children with the most common type, acute lymphoblastic (ALL), now spend very little time hospitalized. The majority of children with acute lymphoblastic leukemia are treated mainly on an outpatient basis making the feasibility of study more difficult. Other more virile types of leukemia are often treated with bone marrow transplantation.
Children with solid tumors (e.g., lymphoma, neuroblastoma, Wilms’ tumor, osteosarcoma, Ewing’s sarcoma, rhabdomyosarcoma, fibrosarcoma) were chosen as the subgroup of childhood cancers for examination in this study for two main reasons. First, treatment for solid tumors often includes other modalities such as surgery and radiation, but these modalities do not usually enter into the protocol until after the first few months of treatment and thus allows for the study of just the effects of chemotherapy. Second, unlike ALL, treatment for solid tumors is often exploratory and intense, causing a more extreme symptom experience.

The third decision made in the effort to identify and define the critical case, which would potentially provide the most information on the treatment experience of childhood cancer, was to define the age range as a school-aged child or young adolescent between the ages of 7 and 16 years. Initially the age boundary was set at 8 to 12 years of age. These age boundaries were chosen to assure that all children would have the minimum cognitive capabilities of Piaget’s concrete operational period (Miller, 1993). Concrete operations are the minimum cognitive capability required to employ the variety of data collection methods that were used in this study. Formal testing of the child for cognitive stage and capability were not conducted in order to decrease the testing burden on the sick child. Also, assigning a child to a cognitive stage based upon age has been shown to account for the majority of variances in cognitive capability (Harbeck & Peterson, 1992). Studies conducted using chronological age have found little differences between its use and the use of testing for cognitive stage (Gaffney, 1993; Harbeck & Peterson, 1992).

A child in the concrete operational period of development has acquired the ability to think logically and has developed an understanding of the concepts of time, space, and
number (Harbeck & Peterson, 1992; Thompson & Gustafson, 1996). It is within this stage of development that the child is able to conceptualize the reversal of processes, such as becoming sick and getting well. These concepts are integral to a study of a transitional state such as symptom distress. The concrete operational period is the stage at which the child can use concepts as representations of his or her thoughts. The explanations given are more likely to be based on causal reasoning, thus allowing for exploration of distress (Bearison & Pacifici, 1989; Munet-Vilaro & Vessey, 1990). Bibace and Walsh (1981), in a study of children's conception of illness, identified categories of illness explanations that were developmentally ordered according to the child's Piagetian cognitive level, and their results provided further support that children's concepts of illness are related to their cognitive developmental levels.

However, the age range in this study was expanded to include children and adolescents 7 to 16 years of age. I made this decision because of an unforeseen lack of newly diagnosed children within this age range across the first 2 months of data collection. Because of the time constraints placed upon data collection in this study, a decision was made to expand the range to include young adolescents. This decision did not violate any methodological or developmental considerations in this study as all instruments used were appropriate for this full range of ages.

The epidemiology of solid tumors supports the decision to use the school-aged child and young adolescent between 7 and 16 years of age as the critical case. The annual incidence of soft tissue sarcomas has been estimated to be 8 per million children less than 15 years of age (Young, Ries, & Silverberg, 1986).
Therefore, the case in this study was a child, between the ages of 7 and 16 years old, who was about to undergo a standardized chemotherapeutic treatment protocol for a solid tumor or acute myeloblastic leukemia. Three critical cases were sampled primarily to help make the symptom profile more visible. The ability to make comparisons among cases illuminates the patterns present. In addition, Stake (1995) cautioned that not all cases work out well. The attrition rates in a study of this design and with this population are potentially very high. Many uncontrollable variables may operate over a 3-month period of study. Although the past decade has seen a dramatic improvement in the treatment outcome of childhood solid tumors, the cure rate for some tumors remains below 60%. Thus, the possibility of death for the children in this study was real. Childhood cancer diagnosis and treatment exert profound stress upon the family. Thus many family variables could have affected how long a child would remain in the study.

Overall, childhood cancer is about one-third more common among boys than among girls. However, the male predominance is less marked in the solid tumors (Stiller, 1997). Therefore, this study was designed to include at least one boy and one girl.

Eligibility criteria included:

1. Boy or girl between the ages of 7 and 16 years living in the same household as a parent or guardian.

2. Presence of a definitively diagnosed solid tumor, about to undergo remission induction chemotherapy.

3. No co-morbidity present upon diagnosis.

4. Willingness to participate in the study as indicated by a signed consent from a parent or guardian and verbal or signed assent from the boy or girl.
5. Able to speak, understand, and read English.

6. Location of household is within 60 miles of the university medical center.

The contribution of parents to their child’s emotional distress and coping responses during adaptation to chronic illness, painful medical procedures and hospitalization has been studied (Banez & Compas, 1990; Bloom, 1975; Jay et al., 1983; Thompson, Gustafson, Hamlett, & Spock, 1992; Wright & Alpern, 1981) with mixed results. Because research shows that a child’s symptom experience is affected by the parents’ experience, the parents were an important part of the context in this study. However, in keeping the main purpose of this study in view, the symptom experience from the child’s perspective, data collection did not take place directly with parents. Osoba (1994) stated that the use of proxy measurement, such as parents, when attempting to learn about quality of life issues potentially clouds the researcher’s view of the patient’s perspective. Also, studies are available in the adult literature of poor proxy–patient agreement (Jachuck, Brierly, Jachuck, & Wilcox, 1982), and poor agreement between the child and parent on behavioral measures, such as emotions and subjective states (Achenbach, McConaughy, & Howell, 1987).

Recruitment

The first potential case was identified in collaboration with the chief pediatric haematologist/oncologist. The physician and I approached the child and a parent or guardian within 2 to 5 days following diagnosis to discuss the study. The time period of 2 to 5 days was chosen because of information obtained from a group of parents and nurses. The rationale included the need to give the family at least 48 hr to begin processing the new diagnosis without missing out on the initial response to the first cycle of chemotherapy. If they expressed an interest, I visited the child and family in the hospital setting to explain the
study's purpose and all methods, to inform them that participation was voluntary, and to make sure they understood they could withdraw from the study at any time without affecting their treatment. Letters of information were left with the child and parent to allow them time to think about their decision. I returned within 24 hr to answer any questions and to obtain written consent from a parent or guardian and written or verbal assent from the child. The institution's human subjects' standards were followed for informed consent and confidentiality (Appendix A). A code number and fictitious name were assigned to each subject and were used as identification on all data collected. The consent forms, list of code numbers, names, and data questionnaires are kept in a separate locked file cabinet.

Once data collection was underway, analysis began immediately to provide information that assisted in selecting the next case. I decided that a minimum of 1 month of data collection must be underway on the first case prior to choosing the second case. However, because of the decrease in number of children newly diagnosed with a solid tumor during the first 3 months of data collection, the first case had completed the study before the second and third cases were enrolled. The second and third cases were enrolled within 1 week of each other. Throughout the sampling and data collection period, the data being collected were evaluated for adequacy. Adequacy refers to the sampling evaluation criteria in which the sufficiency and quality of the data are examined (Morse, 1986). The completeness and amount of information collected from each case were evaluated in terms of the data's contribution to understanding the symptom experience.

Setting

The setting for this study was a university-based medical center in the southern United States that provides comprehensive care for pediatric hematological and oncological
disorders. At the time of data collection, the hospital had 28 beds on the pediatric hematology-oncology unit, including bone marrow transplantation. Their records indicated that approximately 20 to 25 new, school-aged children are diagnosed with a solid tumor each year. A multidisciplinary team representing medicine, nursing, nutrition, child life, social work, education, psychology, and physical therapy provided care for children admitted to the unit. Data collection took place in the hospital, the pediatric outpatient clinic, and in the child’s home.

Data Collection

The data collection period covered 3 months of the initial chemotherapeutic treatment protocol. To make symptom patterns visible and to capture the day-to-day changes in the symptom experience, data were collected as frequently as possible. Conversely, I remained aware of the potential burden of this methodology on the child and balanced the decision regarding how many observations to make (Franklin, Allison, & Gorman, 1997).

The chemotherapeutic treatment protocol for a solid tumor is highly variable depending upon the tumor type, staging of the tumor, tumor histology, and site of primary tumor. In general, treatment can be divided into two main segments, a phase II window and regular therapy.

Prior to initiation of regular therapy, there is generally a period of treatment called the phase II window, which generally consists of two courses of a drug (or novel combinations of drugs) that are being tested for efficacy in previously untreated patients with given tumors. There is no specific remission induction, consolidation, or maintenance phase as with acute leukemia. Radiologic imaging studies are done pretreatment and then before each course of
the Phase II Window to gauge the response. If there is progressive disease, the patient goes
directly into regular treatment.

Instruments

Three kinds of data collection techniques were used to ascertain the treatment
experience related to fatigue, anorexia, nausea, vomiting, pain, mood alterations, stress, sleep
alterations, and overall symptom experience. The first kind included the self-report
instruments: a symptom diary, a pain scale, and a nausea and vomiting scale. The second kind
of data collection technique was the narrative interview. It is becoming more widely accepted
that children are the best sources of information about themselves (Bearison, 1991; Deatrick
& Faux, 1989; Thompson & Gustafson, 1986). In exploratory research, the subjective
reporting of informants from their own perspective should be the primary source of data
collection (Folkman & Lazarus, 1984; Sorensen, 1989). This was particularly true in this
investigation with children who existed in the “unique culture of childhood” (Yamamoto,
Soliman, Parsons, & Davies, 1987). The third kind of data collection technique included the
biobehavioral measures: salivary cortisol measure and actigraph sleep measure.

Self-Report Instruments

Symptom Diary

A symptom diary has been found to be an economical means of collecting a large
amount of data from adults over a prolonged period of time (Lewis, 1995). A diary has an
advantage over the interview in that events are often recorded shortly after they occur,
providing more accurate information than recall data obtained in a retrospective interview.
While providing the necessary structure that children need for reporting subjective experience
(Sorensen, 1989), a diary also allows the children to express their unique perspectives.
Several researchers have used the diary for data collection with children and have found it to be a particularly useful method of collecting data on symptoms associated with many chronic illnesses (Brown, Rowley & Helms, 1994; Butz, 1987; Kotzer, 1990; Shapiro et al., 1995; Sorensen, 1989). More specifically, a diary has been used with samples of 11 through 17 year olds with cystic fibrosis (Brown, Rowley, & Helms, 1994), 7- through 11-year-old healthy children (Bianchi & Robinson, 1997; Sorensen, 1989), 7 through 12 year olds with asthma (Butz, 1987), and 7- through 17-year-olds with sickle cell disease (Shapiro et al., 1995). All researchers found the diary to be effective for studies of symptomatology and of eliciting self-reported experiences longitudinally and daily.

Diaries have been used with adults to describe a broad array of chronic and short-term illnesses and health behaviors (Gong, Simmons, Clark, & Tashkin, 1988; Lewis, 1995; Rakowski, Julius, Hickey, Verbrugge, & Halter, 1988; Rogers, Caruso, & Aldrich, 1993; Woods, 1987). Carp and Carop (1981) determined criterion validity in a 7-day diary study with adults by demonstrating a significant correlation between diary scores and interview data measuring daily activities.

Response rates in diary studies with children have been reported to be 58% (Brown, Rowley, & Helms, 1994), 75% (Shapiro et al., 1995), and 88% (Butz, 1987). Diary design, remuneration, telephone surveillance, and biweekly reward were suggested as crucial to maintaining the high completion rates in children (Butz, 1987). In terms of diary design, Sorensen (1989) suggested keeping the diary as structured as possible while allowing for some open-ended responses.

The diary used in this study was called the Symptom Diary. This sticker-journal-type diary consisted of nine pages for each day the child was enrolled in the study (see Appendix...
B). The diary was designed to allow the participants to use stickers to indicate their levels of symptoms, twice daily, at midmorning and before bedtime, over the 3-month period. The first page consisted of self-report scales that tracked the occurrence and severity of fatigue, pain, worry, mood alterations, and general well-being. Pain, fatigue, and worry were measured on a Likert scale that ranged from 1 (not at all) to 5 (the most possible). Mood was rated using stickers of faces that indicated happy, sad, mad, and lonely. The construct of mood as measured in this study referred to the moment-to-moment affective state of the children as opposed to a more stable enduring characteristic. General well-being was evaluated in an open comment section in which the children were told they could write about or draw anything related to how they were feeling at that point in the day. On this first page, the children also recorded the time they fell asleep the previous night and woke up the following morning. This first-page format, called the morning page, was also repeated for the evening page.

The Pediatric Nausea, Vomiting, and Retching Guide (PNVR)

The second, third, and fourth pages of the diary consisted of the Pediatric Nausea, Vomiting, and Retching Guide (PNVR). The PNVR guide was used to collect data on the frequency, duration, severity, and bother of nausea, vomiting, and retching. As discussed previously, although nausea and vomiting have been studied in children, most of the instruments used were versions of adult instruments (Benoit et al., 1995; Dick, Meller, & Pinkerton, 1995; Foot & Hayes, 1994; Jacknow, Tschann, Link, & Boyce, 1994; Nahata, Ford, & Ruymann, 1992; Tyc et al., 1995; Zoubek, Kronberger, Puschmann, & Gadner, 1993). There is a need to develop methodologically sound instruments to measure constructs such as symptoms in children. Accordingly, I used an unpublished, recently constructed and
pilot-tested PNVR guide (Geib & Wright, 1998), which was designed to measure nausea, vomiting, and retching in 5- to 12-year-old children with cancer. This instrument was administered twice daily, at midmorning, and prior to bedtime, throughout the 3-month period of the study.

The PNVR Guide was developed from interviews conducted with three healthy children, one hospitalized child, and three hospitalized children who experienced nausea, vomiting, and retching as a result of chemotherapy for cancer (Geib & Wright, 1998). Parents of the seven children and two pediatric oncology staff nurses were also interviewed during instrument construction. The interviews were used to isolate specific terms and phrases that children used when attempting to communicate nausea, vomiting, and retching. A study by Zeltzer and colleagues (1988) lends support to the use of a rating scale with children as young as 5 years of age when asking them to respond to questions of time and bother regarding symptoms such as nausea and vomiting.

In this study, I used the portions of the PNVR Guide that measured the concepts of nausea duration and severity, vomiting frequency, retching frequency, and bother of nausea, vomiting, and retching. Duration referred to the length of time the child felt nauseous. Frequency referred to the number of occurrences of vomiting or retching. Bother represented emotional distress of nausea, vomiting, retching, or all three (Geib & Wright, 1998).

Scores on the nausea duration portion ranged from 1 (my stomach has hurt none of the time) to 4 (my stomach has hurt all of the time). Scores on the vomiting frequency portion of the scale ranged from 1 (threw-up 0 times) to 6 (threw-up more than 4 times). Scores on the retching frequency portion of the scale ranged from 1 (I tried and nothing came out 0 times) to 6 (I tried and nothing came out more than 4 times). The nausea, vomiting, and
retching bother scales consisted of a vertical visual analogue scale that measured 5 mm in length. Scores on the bother scales ranged from 1 (*not bad at all*) to 5 (*as bad as it could be*).

**The Oucher Scale**

The fifth page of the Symptom Diary consisted of the Oucher Scale (Beyer, Villarruel, & Denyes, 1995) that was used to measure pain perception. The original purpose of the Oucher Scale, developed in 1980 as a self-report of pain intensity for white children 3 to 12 years old (Beyer, Denyes, & Villarruek, 1992), was to provide a developmentally appropriate, appealing, and valid method to measure pain in children. Pain perception, in this study, was defined as the degree of discomfort produced by any source experienced by a child while in treatment. The primary theoretical foundation for the Oucher is that the cognitive level of the child will influence his or her ability to describe the abstract concept of pain. Research has supported that children as young as 3 years can identify the varying intensities of their pain experiences by using self-report scales (Eland, 1990). Since its development, several alternate ethnic (Hispanic, African American) versions have developed and have reported acceptable reliability and validity indices (Jordan-Marsh, Yoder, Hall, & Watson, 1994).

The Oucher consists of two vertical, separate scales on a laminated poster: (a) six photographs of a preschool child reflecting a continuum from no hurt (*bottom picture = 1*) to the biggest hurt (*top picture = 6*) on the right and (b) a numeric rating scale (0 to 100) on the left (see Appendix B). The poster format allows the child to point to their selection. The two separate scales are to be used for children with differing cognitive abilities. Younger children use the photographs and older children use the numeric rating scale. In this study, the numeric scale was used to assess pain levels twice daily, at midmorning and before bedtime. Thus scores could range from 0 (*no pain*) to 100 (*the most pain possible*). During the first 2
weeks of data collection, the investigator gave the child instructions in using the Oucher. After the first 2 weeks, the child was given a Casio electronic watch that alerted him or her midmorning and prior to bedtime, to use the Oucher and to record the score in the Symptom Diary. The ethnic version that corresponded to the child's ethnicity was used.

The Oucher has been used on children 3 to 18 years old for a variety of procedure-related pain and pain-producing illnesses and has demonstrated strong psychometric properties. Extensive methodological testing of the original Oucher has established the content, convergent, discriminant, and construct validity of this tool (Aradine, Beyer, & Tompkins, 1987; Beyer & Aradine, 1986, 1987, 1988) and the test-retest reliability (Belter, McIntosh, Finch, & Saylor, 1988), all of which have acceptable levels. The photographic and numerical scales were highly correlated ($r = .82$). Correlations between the Oucher and other self-report pain intensity rating tools, such as a visual analog scale and the Poker Chip tool, have been substantial ($r = .88$ and $r = .98$, respectively) (Aradine, Beyer, & Tompkins, 1987).

The first four pages of the diary were repeated for an evening scoring. One weakness noted in using the diary for data collection with children was an inability to clarify beyond the diary entries (Kotzer, 1990). In this study, the diary was used as an elicitation tool in the biweekly narrative interviews. Thus, any one symptom could be probed and focused upon during the interview. I visited each child twice daily while they were hospitalized and at least twice a week while they were at home to ensure the completeness and accuracy of the diary and other data collection techniques.

**Revised Children’s Manifest Anxiety Scale**

The Revised Children’s Manifest Anxiety Scale (RCMAS) was administered to the children once a month while they were in the study. This instrument was chosen to measure a
more enduring, stable aspect of anxiety that may be less affected by moment-to-moment fluctuations. This instrument, subtitled “What I Think and Feel,” is a 37-item, self-report instrument designed to assess the level and nature of anxiety in children from 6 to 19 years of age (Reynolds, & Richmond. 1990). In addition to providing a Total Anxiety score, the instrument also has four subscale scores that are labeled: (a) Physiological Anxiety, (b) Worry/Oversensitivity, (c) Social Concerns/Concentration, and (d) Lie. These subscales represent areas in which anxiety may be manifest. The scores are derived from the child’s affirmative responses and thus a high score indicates high anxiety. The scale’s authors provide norms based upon samples at 1-year intervals. For the Total Anxiety score, the standard score has a mean of 50 and a standard deviation of 10. Thus, any score above 60 indicates a child is experiencing high anxiety. For the subscales, scaled scores have a mean of 10 and a standard deviation of 3. Thus any subscale score greater than 13 indicates a child is experiencing high anxiety related to the particular area assessed by that subscale.

**Narrative Interviews**

Narrative interviews, the second method of data collection, were conducted at four points in time spread out over the 3-month study period. The interviews were semi-structured and lasted no longer than 30 to 40 minutes. I used the Symptom Diary as an elicitation tool during the interview to give the child an ongoing reminder of the interview’s purpose. This technique allowed me to get clarification of any journal entry. The interview used in this study was event and data driven, as opposed to being fixed prior to the study’s initiation, because the interview could be changed in the course of the study as events in the study and the nature of the data collected made such a change necessary.
The purpose of the interview was made very clear to the child. Questions focused on the child's personal experience with and perception of the symptom experience. The interview had an open-ended semi-structured format. Each child was asked to tell everything that happens when he or she gets treatment, what happens when he or she gets chemotherapy, and how does getting medicine for cancer make him or her feel. The goal was to elicit the children's narrative's of their perceptions and experiences without influencing their responses. More focused questions followed any leads regarding specific symptoms or illness experiences.

The interviews focused on several facets of the symptom experience, including perceived vulnerability to symptoms, overall assessment of the day, bothers and worries, and physical experience. The child was given maximum control over the order and manner in which their experiences were relayed. This freedom has been shown to yield information regarding previously unknown facets of the child's experience (Engel, 1995; Garbarino & Stott, 1992). Each child was interviewed individually in their hospital room or in a quiet room at home and was told that the questions were about what happens when children get their treatment. Parents were given the option of being present during the interview.

Scholars in a variety of fields and with different interests have found that children as young as 3 years old can give graphic descriptions of and have excellent recall of experiences related to adverse events such as illness (Alex & Ritchie, 1992; Bearison, 1991; Woodgate & Kristjanson, 1996; Yoos & McMullen, 1996), disaster (Coffman, 1994), and violence (Farver & Frosch, 1996; Miller, 1996). Bearison and Pacifi (1989) studied how children with leukemia organize schematically event representations of their treatment in outpatient pediatric oncology clinics and described how their event representations varied as a function
of age, gender, prognostic condition, and time in treatment. Age and event topic (they were also asked about “going to a birthday party and to a restaurant”) were associated with significant differences among indices of their script knowledge. However, length of time in treatment, prognostic condition, and gender were not significant (Bearison & Pacifi, 1989). This study supported the notion that children’s knowledge of cancer treatment is well established early in treatment, regardless of the severity of their prognoses. Children were found to possess well-organized knowledge of the various events they experienced in oncology clinics. Bearison and Pacifi’s findings affirmed the feasibility of using script methodologies to obtain data regarding children’s narratives of their knowledge and reaction to medical procedures and treatment. All of the children in the Bearison and Pacifi study willingly and spontaneously produced narrative accounts of their visits to the clinics.

In addition to the structured interview sessions, I kept detailed field notes regarding any discussions the children had with me regarding their symptom experience. These discussions took place while undertaking a leisure activity, such as playing a board game. Within 15 minutes of any relay of information regarding symptoms, I would record all the data I could recall. Similarly, I kept field notes while observing the children in interactions with their parents and the pediatric hematology/oncology team. These field notes were recorded nonsystematically and were unstructured.

**Biobehavioral Techniques**

Salivary cortisol levels were taken to measure adrenocortical activity in adaptation to the stress and challenge of the symptom experience. Physiological stress is often measured using biochemical measures, such as epinephrine, norepinephrine, and cortisol, that reflect the endocrine system’s activity (Baum, Grunberg, & Singer, 1982). The physiological
response to stressors is a protective device that maintains homeostasis and is initiated in the hypothalamus. Measuring adrenocortical activity as an indicator of adaptation to stress has been well documented for two decades (Gunnar, 1986; Tennes & Mason, 1982; Tepperman, 1980). The advent of cortical assaying procedures from small samples of saliva has allowed more widespread use of this measure. Results reported by Tennes and Kreye (1985) confirm the relationship between stressful stimulation and elevations in cortisol levels.

The cortisol response to stress has been diagrammed as a triangle and has been appropriately called the HPA axis (hypothalamus–pituitary–adrenal–axis) (McCance & Heuther, 1996). This response begins when a stressful encounter or stimulus signals the hypothalamus to secrete corticotropin-releasing factor (CRF). CRF leads to the production and release of adrenocorticotropic hormone (ACTH) into the general circulation. ACTH then stimulates the release of cortisol from the adrenal cortex as a chemical response to the stressor within minutes of the initial confrontation (Boyce & Jemerin, 1990). Cortisol responses to stressors decrease rapidly and are associated with feelings of discomfort and anxiety. Without giving much detail, levels of circulating cortisol affect the function of the following mechanisms: carbohydrate and lipid metabolism, protein metabolism, inflammatory effects, immune reserve, digestive function, urinary function, connective tissue function, muscle function, bone function, vascular system and myocardial function, and central nervous system function (McCance & Huether, 1996).

Adrenocortical activity exhibits a circadian rhythm in cortisol production (Tepperman, 1980). Almost 90% of daily cortisol is produced in the early morning hours (between 0400 and 0600 hours). Cortisol levels then decline slowly over the morning hours and gradually decline throughout the rest of the day to reach a nadir around midnight. This
circadian pattern of a single, early morning peak has been shown to be present in infants at 3 months of age (Larson, Gunnar & Hertsgaard, 1991).

Measuring cortisol in plasma and hydroxycorticosteroids in urine has typically assessed adrenocortical function. However, blood sampling is accompanied by stress that may modify or heighten the cortisol response, and urinary studies are complicated by difficulties in collection (Krieger, 1973). To overcome these difficulties, researchers have begun using saliva as a means of measuring cortisol levels. Assessment of adrenal status by measuring cortisol in whole saliva has been demonstrated to be a useful alternative to assaying cortisol in plasma and urine as noted in a review of studies utilizing steroids in saliva for assessing endocrine function (Riad-Fahmy, Read, Walker, & Griffith, 1982). Most studies have utilized adult subjects because of the ease of obtaining samples from adults but have found very high correlations between plasma cortisol and salivary cortisol levels (Peters, Waler, Riad-Fahmy, & Hall, 1982; Price, Close, & Fields, 1983).

In this study, salivary cortisol levels were collected at 1000 and 1800 hr daily throughout the 3 months of therapy. Lentz (1989) suggested that a general rule of sampling requires a rate fast enough to obtain two data points per the fastest cycle. Because the cycle occurs throughout the 24-hr day, two measurements in a day are required to capture the pattern. Normal salivary cortisol levels are dependent on not only time but also on the child's age. Normal levels for a child between the ages of 5 and 8 years are 10.9 μg/dl (SD = 5.9) in the early morning and 2.7 μg/dl (SD = 2.5) in the evening. Normal levels for a child between the ages of 8 and 18 years are 10.9 μg/dl (SD = 5.4) in the early morning and 3.1 μg/dl (SD = 3.2) in the evening (Kiess et al., 1995).
One central factor in using this biobehavioral measure with this population is that most children undergoing cancer treatment also receive periodic administrations of exogenous cortisone in the form of dexamethasone as a treatment for nausea. Thus, the researcher must ascertain whether children on exogenous sources of cortisol will be able to (a) maintain a cyclical (circadian) pattern of cortisol levels, or (b) mount an HPA axis stress response. Importantly, the aim in using this measure is to assess the variability in the levels and the effect that the changing symptom patterns have on this variability. The aim is not to establish whether children undergoing cancer treatment have levels that equate with the norm for the age and sex. There are no studies available that have addressed the issue of using cortisol measures with children undergoing cancer treatment. However, a few studies in other populations are instructive. Several researchers have tested the effect of high-dose steroid therapy used with preterm infants and have found impaired production of ACTH (Ford et al., 1997; Rizvi, 1992). They have noted that the cortisol response returns to normal very shortly after discontinuation. Others have looked at the negative feedback action of exogenous glucocorticoids on the HPA axis changes with age in the elderly (Huizenga et al., 1998). These researchers found a lot of intra-individual stability in serum cortisol levels. Thus, despite the suppression, they did see some patterning. They also found that those with the highest baseline cortisol concentrations also had the highest post-dexamethasone concentrations. This finding indicated a close relationship between basal cortisol levels and the feedback sensitivity of the HPA axis to a low dose of dexamethasone. In one study, researchers evaluated basal salivary cortisol and cortisol suppression following dexamethasone administration in adolescents exposed to two levels of extreme trauma (1988 Earthquake in Armenia, Armen et al., 1996). Despite the dexamethasone administration,
there was a significant difference in cortisol levels between the children from the two levels of trauma.

In this study, saliva samples were obtained using the Saliva Sampler (Saliva Diagnostic Systems). The collection procedure involved placing a straw-like collector under the child’s tongue and instructing the child to close his/her mouth. A color-indicator strip turns blue when sufficient saliva has filled the collector. The collector is then inserted into a transport tube.

During hospitalization periods, I collected the saliva samples myself and then transported them in a small cooler to the refrigerator in the biobehavioral laboratory. When a child was at home, he or she collected the saliva samples and then placed them in a large cup that was kept in the refrigerator. At the beginning of the study, each child was given a Casio watch set to beep at 1000 and 1800 hr to remind him or her to collect the saliva sample. Once per week, the cortisol samples were processed into cryotubes and placed in the deep freezer in the biobehavioral lab to await radioimmunoassay for unbound salivary cortisol. The reliability of the lab data was estimated using a double simultaneous reading on all samples.

The actiwatch was used to measure each child’s sleep alterations throughout each night over the 3 months of the data collection period. The actigraph (also referred to as an actometer or actimeter) is a small portable device (the size of a digital wristwatch) that senses physical motion and stores the resulting information. The device can be used in the evaluation of sleep-activity cycles on the basis of a miniaturized acceleration sensor that translates physical motion into numeric representation. This numeric representation is sampled frequently (e.g., every 10th of a second) and aggregated at a constant interval.
(epoch) (e.g., 1 min). These epoch-by-epoch samples are stored in the device’s internal memory until the stored information is downloaded to a computer.

Although sleep alterations have been measured using sleep diaries and parental reports, research findings have suggested that the accuracy of parent-reported sleep habits and the potential confounds in obtaining sleep and behavior reports from the same informant is difficult (Tobia, Wolfson, & Gallagher, 1995). These researchers suggested using the actigraph as a more objective measure of sleep. The unique feature of the actigraph that differentiates it from early technologies is its portability. The actigraph can be attached to a child’s wrist (or ankle) for prolonged periods of time and provides continuous activity data with little interference or few limitations imposed on the subject (Sadeh, Hauri, Kripke, & Lavie, 1995).

The actigraph is initiated by a software program and requires no further manipulation or installation, except for attaching it to the subject’s hand or leg for the duration of the monitoring period. The actigraph was placed on the child’s nondominant wrist (Sadeh, Hauri, Kripke, & Lavie, 1995) at bedtime and was removed upon waking. An Automatic Scoring Analysis software program measured sleep onset time, sleep duration, sleep percent, number of sleep–wake state transitions, number of awakenings longer than 5 min, percentages of “quiet sleep,” percentage of “active sleep,” and the longest continuous period scored as sleep without any identified awakening (Sadeh et al., 1991). I piloted the methodology described above on two boys aged 11 and 13 years’ old.

The actigraph’s reliability and validity have been demonstrated. Validation studies are based on concomitantly obtained actigraph and polysomnographic records. Polysomnographic recordings (PSG) have been used as the gold standard in these studies.
Since the late 1970s, a growing number of studies have demonstrated the validity of modern actigraphy in distinguishing between sleep and wakefulness and in providing useful and reliable measures of sleep–wake organization and sleep quality. These studies have addressed normal samples and clinical samples from ages ranging in infancy to adulthood. Mullaney, Kripke, and Messin (1980) demonstrated that a trained scorer could manually score actigraphic data to distinguish sleep from wakefulness with 91.6% agreement with EEG-based scoring in a group of 102 adult subjects. Actigraph and PSG whole-night sleep measures such as total sleep period, total sleep time, and wake after sleep onset were highly correlated ($r = 0.90$, $r = 0.89$, and $r = 0.70$ respectively).

Webster, Kripke, Messin, Mullaney, and Wyborney (1982) developed an automatic-scoring algorithm for actigraphic data in a series of three experiments. Their findings indicated that automatic scoring is not only fast and objective but also yields high agreement rates with PSG scoring (above 93% with a sample of college students). Sadeh and colleagues (Sadeh, Alster, Urbach, & Lavie, 1989; Sadeh, Lavie, Scher, Tirosh, & Epstein, 1991) conducted two studies that demonstrated the validity and the clinical potential of actigraphy. In the first study, an algorithm based on discriminate analysis was developed and validated against PSG with large samples of normal adult subjects, children, insomniacs, and sleep apnea syndrome patients. Minute-by-minute agreement between actigraphic and PSG scoring was 90.2% for normal adults, 89.9% for children, 78.2% for insomniacs, and 85.7% for patients with sleep apnea. The second study extended the use of the derived scoring algorithm to younger children and infants (1 to 4 years), resulting in 85.3% agreement between actigraphic and PSG sleep–wake scoring agreement. In comparing actigraphy with sleep logs, Hauri and Wisbey (1992) found that the actigraph came considerably closer to the data.
obtained from PSG than did the sleep logs of adult subjects. Research has also shown that the actigraph is most useful for assessing longitudinal treatment or experimental processes because of high within-subject correlations, suggesting a consistent actigraphic estimation error from night to night (Chambers, 1994).

Sadeh, Lavie and colleagues (1991) reported developmental trends of actigraphic sleep–wake measures in sleep-disturbed and control toddlers aged 9 to 24 months. They found that age was significantly correlated with sleep-schedule measures such as sleep-onset time ($r = 0.39; p < .05$) and nocturnal sleep duration ($r = -0.53; p < .005$).

A few studies used the actigraph to report on patients with affective disorders such as depressed adults (Royant-Parola et al., 1986), manic-depressive adults (Wehr, Goodwin, Wirz-Justice, Breitmaier, & Craig, 1982) and children with attention deficit hyperactivity disorder (Bunney, 1983; Porrino et al., 1983; Tirosh, Lavie, Sadeh, Munvez, & Lavie, 1994).

Actigraphic data can be scored by visually inspecting raw actigraphic-activity data and judging whether the subject is asleep or awake in any given time during the study period. However, in this study, automatic scoring was used as the raw actigraph-activity data were stored in digitalized computer data. Computer algorithms were developed for automatic sleep–wake scoring and automatic generation of summary statistics.

Data Analysis

Data analysis focused on understanding each case alone, in its entirety. I began by coding the data and then placing them into data displays. Once the data were placed into displays, I was able to draw conclusions by noting regularities, patterns, possible configurations, and causal flows. This conclusion-drawing step included verifying my conclusions by returning to the data. I looked for within-case generalizations that could be
made. While analyzing each case alone, I was simultaneously looking for any processes or structures that were or were not at the core of all three cases.

Once each case was analyzed and described alone, I began the process of cross-case comparisons to search for any structure that was shared by all three cases. I looked for cross-case generalizations.

**Self-report and Biobehavioral Techniques**

I examined each case using visual inspection of the graphed self-report and biobehavioral data. Many researchers and authors support and encourage visual inspection and graphic analysis of single-subject data and, although it is one of the oldest forms of analysis, it remains extremely resilient (Franklin, Gorman, Beasley, & Allison, 1997; Kratochwill, 1992; Parsonson & Baer, 1992). I placed the measure of time on the abscissa and the individual symptoms on the ordinate, which allowed an overall inspection of any possible patterns or cycles in the symptom data. The graphed data was examined for trends, periodicity, and variability (Gorman & Allison, 1997). The graphs allowed me to make hypotheses about the relationships or lack of relationships among individual symptoms.

Descriptive statistics such as means and ranges were also used with caution. The purpose of this study was to describe the children's symptom patterns over time and thus the analysis techniques focused on pattern, change, and variability over time rather than on absolute values.

**Narrative Interviews**

To obtain a description of each child's symptom distress experience, I analyzed the narrative interview data using a content analysis technique. Importantly, I conducted this analysis concurrently with data collection. Because the study's goal was to explore the
symptom experience from the child's perspective, I used an open category style without pre-established categories. To look for patterns that connect various themes, I used the analytic strategy guided by Miles and Huberman's (1994) method for data management. According to these researchers, when conducting research where connections among elements are sought, the analytic process must be accompanied by the researcher's constant search for patterns in the data that suggest certain pieces of data belong together, or that an individual piece is an instance of a more general class of events or ideas. Miles and Huberman's (1994) strategy for seeing relationships in large volumes of data, as in this study, is the construction of a matrix display and process or sequence maps. Importantly, these displays allowed for the comparison of any symptom patterns that evolved from the narrative data to symptom patterns that appeared in the self-report and biobehavioral data.

I analyzed the interview data to discover regularities and to identify and categorize patterns. The guiding philosophy of the content analysis was to allow the data to suggest themes without my making an a priori proposition (Sandelowski, 1993). I read each narrative as a complete unit while trying to ascertain the story the child was trying to tell. While reading, I constantly searched for recurrent words or images, central metaphors, emotions, contradictions, inconsistencies in style, revisions, or absences in the story as well as shifts in narrative voice (the use of first and third-person voice) (Brown & Gilligan, 1991).

During the second reading of the narrative interview, I conducted line-by-line coding of the data that allowed me to break them down into the smallest pieces of data that could stand alone (Tesch, 1990). From these pieces of data, I developed general categories.

Once the coding was complete, I studied and systematically explored the categories for specific configurations that generated meaning. They were also studied for linkages across
categories. Interpretation followed, in which I attempted to understand the configurations and patterns identified by inspecting the themes and regularities as well as contrasts, paradoxes, and irregularities (Coffey & Atkinson, 1996; Tesch, 1990).

A final, yet important step in the overall analysis was to compare the patterns and configurations from the self-report and biobehavioral data with the patterns and configurations of the narrative data. The results from the two types of analyses were examined for confluence among symptoms and the development of trends.

**Human Subjects**

I obtained approval for this research study from the university medical center’s Review Board for Research Involving Human Subjects and the Cancer Protocol Review Committee. Each prospective child and parent received a detailed verbal and written explanation that described the study, potential benefits, data collection procedures, and a guarantee of data anonymity. I assured each child and parent that refusal to participate in the study would have no bearing on the care they received at the hospital. The child and parent were given an opportunity to ask questions before signing the consent form.

Attrition rates in longitudinal studies are a well-known problem that increases exponentially as the length of the study increases (Given, Keilman, Collins, & Given, 1990). Loss of subjects in this study was potentially very high because of the burden on the child and family or because of the morbidity and mortality associated with the illnesses being studied. The 3-month data collection time period was short enough to help decrease voluntary loss of subjects. Also, the case study design allowed me to develop a close relationship with each child and family. Incorporated into the study design was a special day for the child called prize day. Once each week the children were allowed to choose from an array of age-
appropriate toys of a value less than $5. This proved to be a very important day for me and the children, and we all looked forward each week to prize day. Once each child completed the 3-month data collection time period, he or she received a $50 gift certificate that could be used at a local book store.
CHAPTER FOUR
ANALYSIS AND INTERPRETATION

The three critical cases examined in this study are named using the pseudonyms, Abby, Michael, and Rachel, which were chosen by the children. The cases of Abby, Michael and Rachel are presented individually, beginning with an analysis of their quantitative and qualitative data and ending with interpretations regarding the individual cases. After all three cases have been presented, cross-case interpretations are presented.

Even though Abby was enrolled into the study last, I chose to present her case first because the completeness and fullness of the data seemed to set up a model from which to read and understand Michael’s and Rachel’s data.

Abby

I first met Abby on January 15, 1999, in the waiting room of a busy pediatric oncology clinic. Abby, a white, 16-year-old female, was sitting with her mother and aunt amidst a handful of much younger children and their parents. Abby had been diagnosed on January 4, 1999, with stage III B Hodgkin’s Lymphoma. She was to begin the chemotherapy portion of her treatment for this disease on January 20, 1999.

Abby had been a healthy adolescent who, until 2 years ago, had lived in Louisiana. Due to changes in her father’s employment status, her family moved to South Carolina where they lived for 2 years until moving to North Carolina in December of 1998. Abby had
enjoyed good health until August of 1998, when she developed vague symptoms including night sweats, pain with inspiration, and fatigue. She had first complained of a sore left leg in early October, and, then, on October 31, she noticed a lump in her inguinal node area that within 1 week, had grown to the size of a tennis ball. As she recalled:

I’d go to school and if anybody made me laugh, it would hurt real, real bad. And shortness of breath. But I didn’t think I didn’t put all these together because they were all so spread out from each other. I didn’t put all these together. And it was just little problems. And I didn’t really think about it. And, so when I was diagnosed, I wasn’t surprised, really, because, I mean, after you put it all together, it’s like, yeah.

Abby did not tell her parents about her symptoms right away because they were about to move to North Carolina. Her first visit to the pediatrician was in December. On January 4, she underwent excision of the inguinal growth and was subsequently diagnosed with cancer. Abby recalled:

The doctor took it out and I guess he had went off and told my parents what he had found. And while I was in recovery, my parents came in and they were all just real shocked, and I just knew right then, that, I knew in my heart that it was cancer.

Abby had a central venous line inserted on January 19 and returned to the clinic on January 20 to receive her first round of chemotherapy. Table 2 shows the timeline of events for Abby.
Table 2

Abby’s Chronology of Diagnostic Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>October, 1999</td>
<td>noticed lump in inguinal region</td>
</tr>
<tr>
<td>December, 1999</td>
<td>moved to NC</td>
</tr>
<tr>
<td></td>
<td>first examination</td>
</tr>
<tr>
<td>January 4, 1999</td>
<td>excision of tumor, dx</td>
</tr>
<tr>
<td>January 19, 1999</td>
<td>port placement</td>
</tr>
<tr>
<td></td>
<td>bone marrow biopsy</td>
</tr>
<tr>
<td>January 20, 1999</td>
<td>Cycle I begins</td>
</tr>
</tbody>
</table>

Treatment Protocol

The relative severity of chemotherapy treatment protocols are often classified based upon their emetogenic potential, which describes the potential that individual agents within the protocol have for causing nausea and vomiting. Emetogenic potentials are classified as (a) severe (more than 90% of persons will experience nausea and vomiting); (b) high (60%-90% of persons will experience nausea and vomiting); (c) moderate (30%-60% of persons will experience nausea and vomiting); (d) low (10%-30% of persons will experience nausea and vomiting); and (e) very low (fewer than 10% of persons will experience nausea and vomiting) (Chase & Staggs, 1990). Of the four agents administered to Abby every 2 weeks, her treatment protocol included one agent classified with as having severe emetogenic potential, one agent as having moderate emetogenic potential, one agent as having a low emetogenic potential, and one as having very low emetogenic potential.
Table 3 shows Abby’s treatment protocol, which entailed outpatient chemotherapy of 12 cycles given at 2-week intervals. Each cycle consisted of an infusion of four agents. Her final infusion was to be given June 24, 1999, and was to be followed by 6 weeks of radiation treatment.

Table 3

*Abby’s Treatment Protocol*

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Protocol Phase</th>
<th>Dates</th>
<th>Chemotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cycle I / Day 1</td>
<td>01/21/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
<tr>
<td>2</td>
<td>Cycle I / Day 15</td>
<td>02/04/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
<tr>
<td>3</td>
<td>Cycle II / Day 1</td>
<td>02/18/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
<tr>
<td>4</td>
<td>Cycle II / Day 15</td>
<td>03/04/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
<tr>
<td>5</td>
<td>Cycle III / Day 1</td>
<td>03/18/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
<tr>
<td>6</td>
<td>Cycle III / Day 15</td>
<td>04/01/99</td>
<td>Bleomycin, Dacarbazine, Doxorubin, Vincristine</td>
</tr>
</tbody>
</table>

Abby was enrolled into the study on January 20, 1999, and recorded data regarding her symptomatology twice daily for 85 days, through April 14, 1999. During this time, she was never admitted to the hospital but spent at least one full day every 2 weeks in the oncology clinic. I conducted data collection supervision visits with Abby twice a week in her home for 12 weeks, during which time I picked up her completed diary sheets, salivary cortisol samples, and downloaded the sleep data into the computer. These supervision visits generally lasted approximately 1 hr. On four separate occasions throughout the data collection period, I conducted a tape recorded interview with Abby. Each of these interview sessions typically lasted approximately 2 hr.
Abby lived with her mother, father, 10-year-old brother, and 20-year-old sister in a four-bedroom home in a middle-class subdivision approximately 20 miles from the university medical center. Abby’s father was employed full time as a parts manager at a car dealership; her mother was unemployed.

**Self-Report Data and Biobehavioral Data**

Data was collected using the following self-report and biobehavioral methods: a daily symptom diary; the Oucher pain scale; the Pediatric Nausea, Vomiting, and Retching scale; the Revised Children’s Manifest Anxiety Scale; salivary cortisol samples: and Sleep Actiwatch.

**Symptoms**

A very important area of the diary for Abby was an open section at the bottom of the morning and evening pages, on which she was told she could write anything that came to her mind about her symptoms for that particular day. Appendix B shows a sample of the dairy pages. Abby was the only child in this study to use this area of the diary daily. She filled in this area with a very detailed elaboration of the symptoms that were addressed in the scales. She also included details about her mood and the type of day she was having.

Abby expressed her symptom experience by describing each treatment symptom under larger, more abstract concepts such as worry and anxiety. In the first month of the study, Abby organized her thoughts about her treatment based upon worry. She worried about which symptoms she would get, how bad they would be for her, and how long they would last. In the second and third months of the study, her worry manifested itself as severe anxiety. While worry was still a central emotion for Abby, she began to talk less about her worry and more about how anxious her symptoms were making her. As time passed in her
treatment, she began to anticipate the symptoms that were to come. This anticipation was exhibited as anxiety. Through the following analysis of quantitative and qualitative data sources I will show how I came to know Abby’s case as one of worry.

Abby received her chemotherapy on the following days over the course of the study: 02, 16, 30, 44, 56, 72. These 6 days of chemotherapy are helpful anchors from which to analyze the symptom patterns that are shown in the figures that follow.

**Pain.**

Abby’s self-report of pain on the Symptom Diary Likert scale ranged from 1 through 5, with a mean pain score of 1.84 (SD = .98). Figure 2 shows how she scored her morning and evening pain over the 85 days in which she participated in the study. As shown in this figure, her levels of morning pain were higher in the first month and continued to decrease over the next 2 months. Her reports of pain at this time of day were quite variable, with high peaks and low valleys occurring regularly. Unlike the first 2 months of the study, she did not experience multiple consecutive painless days in the last month of the study.

Abby’s evening pain scores were more intense than her morning pain. She had much higher pain peaks in the evening that endured throughout the length of the study. Table 4 shows the difference between the mean and variance of her morning and evening pain scores.

The second measure of pain included in the daily diary was the Oucher pain scale. As expected, there was a large positive correlation (r = 0.63, p = .000) between Abby’s Likert pain rating and Oucher rating scores. The Oucher scores ranged from 0 through 80, with a mean pain intensity score of 34.75 (SD = 22.12). Thus, while her pain levels on this instrument were highly variable, they were, on average, in the mildly uncomfortable zone.
Figure 2. Abby's AM and PM pain over time.
Table 4

*Abby’s Mean Symptom Scores*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Scores</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>Morning</td>
<td>Evening</td>
<td>Morning</td>
<td>Evening</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Pain</td>
<td>1.84</td>
<td>0.98</td>
<td>1.75</td>
<td>0.94</td>
<td>1.94</td>
</tr>
<tr>
<td>Oucher</td>
<td>34.75</td>
<td>22.12</td>
<td>32.47</td>
<td>20.83</td>
<td>37.09</td>
</tr>
<tr>
<td>Fatigue</td>
<td>3.66</td>
<td>0.96</td>
<td>3.64</td>
<td>0.93</td>
<td>3.67</td>
</tr>
<tr>
<td>Worry</td>
<td>1.26</td>
<td>0.50</td>
<td>1.25</td>
<td>0.51</td>
<td>1.27</td>
</tr>
<tr>
<td>Nausea frequency</td>
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<td>2.00</td>
<td>0.87</td>
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<td>6.34</td>
<td>9.24</td>
<td>6.34</td>
<td>8.41</td>
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</tbody>
</table>

Figure 3 shows Abby’s morning and evening Oucher scores over the 85 days in which she participated in the study. There is no evident decrease in the intensity of Oucher scores over the course of the study, as was seen with the morning pain scores. This result may be because the Oucher, with its potential range of 100 points, allows for a more sensitive and precise assessment of pain intensity. While her Oucher scores are quite variable and on the mildly uncomfortable level, she did not experience multiple consecutive days of no pain. Abby’s evening Oucher scores were consistently higher than were her morning pain scores, and she experienced little relief in the form of consecutive days without any pain.
Abby’s chemotherapeutic treatment regimen entailed a cycle being administered every 14 days. She experienced six such treatments over the 85 days in the study. During data collection, I became aware through her interview data and narrative diary notes that there seemed to be particular days, following chemotherapy administration, on which her symptoms were more intense. Thus, in addition to plotting her symptoms over the 85 consecutive study days, I also analyzed them using the time factor of number of days post chemotherapy administration. Accordingly, her time in the study can also be described as (a) Day 0 – chemotherapy administration day; (b) Day 1 – one day since chemotherapy administration; and (c) Day 2 – two days since chemotherapy administration, and so forth. Each category of day since chemotherapy administration occurred six times throughout the 85 days of the study.

As shown in Figure 4, which plots Abby’s morning pain by number of days following chemotherapy administration, her pain levels were the highest at 5 days since chemotherapy administration. A span of higher pain scores run from 4 days since chemotherapy administration through 8 days since chemotherapy administration. The pain levels then began to decrease over the remaining 6 days. At 14 days since chemotherapy administration, her pain scores were at their lowest. This category also represents the day prior to her next cycle of chemotherapy. Abby’s evening pain scores were similar to her morning pain scores except for the 2 days prior to the most intense day (Day 5). In the evening, Abby experienced a similar pain intensity on Day 3 and Day 4 as she did on Day 5. Once again, the pain scores decreased over the cycle, with the lowest pain score occurring on the day before chemotherapy administration.
Figure 4. Abby's AM and PM pain by day since treatment administration.
Figure 5 shows Abby’s morning and evening Oucher scores, categorized by day since chemotherapy administration. The pattern shown in this figure is very similar to that found on the Likert pain figure, in that there is a peak pain intensity at Day 5. Her evening scores were higher and more variable than were her morning scores. Her Oucher scores were at the lowest point on Day 13 and then increased on Day 14.

In summary, over the course of the study, Abby’s experience with pain was that of moderate intensity. Although there was a lot of variability in the patterns, the range of scores seldom reflected periods of time with no pain. A trend of higher pain peaks occurred in the first month of the study time, but pain scores remained of moderate intensity throughout the following 2 months. In the evening hours, Abby experienced more intense pain than she did in the morning hours. The pattern of higher pain scores surrounding 5 days post-chemotherapy administration possibly reflects the pharmacological theoretical notion of the nadir period in which the chemotoxic effect on cells is at the highest and most intense level (Balis, Holcengerg, & Poplack, 1997). During the nadir period, cell death is at the maximum. Importantly, Abby did not experience many consecutive days in the absence of pain.

Fatigue

Abby’s fatigue scores were of high intensity throughout the study. Her fatigue (see Table 4) ranged from a 1 through 4, with a mean fatigue score of 3.66 (SD = 0.96). There was no real difference between her mean morning and evening fatigue scores. Figure 6 shows Abby’s morning and evening fatigue scores across her time in the study. The pattern shows she experienced a consistently high level of fatigue throughout the 85 days of the study. There were only two points in the curve at which the level dropped below a score of 2.
Figure 5. Abby's AM and PM Oucher by day since treatment administration.
Figure 6. Abby's AM and PM worry over time.
Figure 7 shows how her levels of fatigue were unchanged throughout the chemotherapy administration time cycle. There was little difference in fatigue levels across the categories of days post chemotherapy, except that by Days 11 and 12, her levels dropped slightly but began to increase again by Days 13 and 14 in anticipation of the next cycle.

Thus, Abby experienced intense fatigue over the course of the study that was not dependent upon time of day, nor which day in her chemotherapy cycle she was at. Over the course of the study, Abby did not habituate to her feelings of lack of energy and weariness.

Worry.

Abby’s level of worry ranged from a minimum of 1 through a maximum of 3. Table 4 shows that her mean level of worry was 1.26 \((SD = 0.50)\), and, as illustrated in Figure 8, there was little difference in the variability and intensity between her morning and evening worry scores. The pattern of worry over the period of the study showed regular peaks of moderate intensity with valleys that indicated consecutive days of no worry.

Abby’s worry scores by day since chemotherapy administration (Figure 9) revealed some effect by time before next cycle. Her evening worry scores began to rise on Days 13 and 14, and her morning worry score was highest on the day she received chemotherapy. This is an interesting finding as Abby usually completed her diary prior to arriving at the clinic for her infusions. Thus, this rise reflects her worry about the pending infusions.

As shown later, Abby’s pattern of worry intensity reflected in the quantitative data conflicts with that of the qualitative data. The quantitative data reflect periodic worry of moderate intensity, with longer periods of no worry. However, the pattern of higher levels of worry immediately prior to and on the day of chemotherapy administration echoes the story of worry that is told in the qualitative data.
Figure 7. Abby’s AM and PM fatigue by day since treatment administration.
Figure 8. Abby's AM and PM worry over time.
Figure 9. Abby’s AM and PM worry by day since treatment administration.
**Nausea.**

Abby’s frequency of nausea scores ranged from 1 to 4, with a mean nausea frequency of 2.20 (SD = 0.99). As shown in Table 4, her mean evening nausea scores were higher than were her morning nausea scores. Figure 10 shows her morning and evening nausea frequency scores over the course of the study. Abby’s morning scores showed a consistent pattern of high peaks once every 10 days, and between the peaks were valleys lasting from 2 to 5 days. This pattern seems to suggest that, over the course of the study, in the morning, she had some relief between very intense periods of nausea. Abby’s evening scores did not show the same pattern. The pattern reflected by her evening scores showed less respite from nausea. Although the intensity of the peaks was the same as in the morning, the valleys were not as low or as frequent. Abby appeared to get less relief from her nausea in the evening. Also, Abby’s nausea frequency did not show change over the course of the study. She did not habituate, or was unable to learn how, to find relief from the nausea, as she received new cycles of chemotherapy.

Figure 11 shows Abby’s morning and evening frequency of nausea scores categorized by day since chemotherapy administration. Her morning scores showed peak nausea on Days 2, 6, and 7, with steadily decreasing nausea prior to the next cycle. Her evening scores showed a much more intense pattern with more days on which she experienced higher levels of nausea. Similar to the morning scores, her evening scores decreased prior to the next cycle. Her evening nausea score on the day of chemotherapy administration was noticeably higher than her morning nausea score was on the same day. This finding is described by Abby in her qualitative data as she talks about how all of the sights, smells, and sounds of the clinic made her feel extremely nauseated even before leaving for home.
Figure 10. Abby’s AM and PM frequency of nausea by day since treatment administration.
Figure 11. Abby's AM and PM frequency of nausea by day since treatment.
Figure 12 shows how bothered Abby felt by the nausea she experienced. The pattern of bother in her morning scores showed she experienced regular high peaks of bother consistently throughout the study. These high peaks were followed by short periods of moderate or no bother. Her pattern of evening bother by nausea showed that the intensity of bother was lower in the first month of the study and then jumped up and remained more consistent during the following 2 months of the study. The peaks that occur in Abby’s bother patterns (Figure 12) correspond with the peaks that occur in her frequency of nausea patterns (Figure 10).

**Vomiting.**

As shown in Table 4, Abby’s frequency of vomiting ranged from 1 to 6, with a mean frequency score of 1.65. As with her nausea scores, her mean evening vomiting frequency was higher than was her mean morning vomiting frequency. The pattern of Abby’s vomiting frequency over time, shown in Figure 13, seemed to increase slightly over the course of the study. This pattern was more evident with her evening vomiting frequency scores that showed very little or no vomiting throughout the first month of the study. The second and third months showed high peaks of increased frequency followed by short periods of no vomiting, with the highest peak occurring in the last 15 days that she was in the study. Her morning scores showed high variability, with very high peaks and a few periods of up to 5 days of low levels or absence of vomiting.
Figure 12. Abby's AM and PM bother by nausea over time.
Figure 13. Abby's AM and PM frequency of vomiting over time.
Figure 14 shows her vomiting frequency categorized by day since treatment administration. Her morning scores showed low levels of vomiting that slowly increased to a peak level at 6 days following chemotherapy administration. This 6-day effect could be a result of Abby reaching her nadir on that day. The pattern then began to drop off and reached the no vomiting level on Day 10 through to the next infusion of chemotherapy. Her evening scores, categorized by day since chemotherapy administration, were quite different. They showed a peak frequency on the day of chemotherapy administration, with slightly decreasing levels over the first week following chemotherapy to a peak at 7 days post chemotherapy. This pattern seems to support the notion that on the evening she received chemotherapy Abby experienced the highest frequency of vomiting. In her qualitative data, Abby talked about how the sights and smells of the clinic, in addition to the experiences associated with the infusions, and then the trip home from the clinic, set off a cascade that culminated in her feeling nauseated and vomiting for the remainder of the evening.

Figure 15 shows Abby’s scores on bother of vomiting. The pattern of bother was very similar to that seen in the vomiting frequency scores. This pattern of increasing scores over the course of the study was somewhat counterintuitive in that Abby did not habituate to her treatment from a vomiting standpoint. Generally, vomiting scores tend to decrease as length of time in treatment increase as a result of factors such as finding the right type of antiemetic to suit the individual. However, this pattern did not appear for Abby. Once again, in her interview data Abby gave some rationale for this pattern of increasing vomiting scores over time.
Figure 14. Abby’s AM and PM frequency of vomiting by day since treatment administration.
Figure 15. Abby's AM and PM bother by vomiting over time.
Retching.

As shown in Table 4, Abby’s retching scores ranged from 1 to 5, with a mean frequency score of 1.51. There was no real difference between her mean morning and evening retching frequency scores. The pattern of Abby’s retching frequency over time, as shown in Figure 16, was one of increasing frequency over the course of the study. Her morning retching scores appeared to peak once every 10 days, with valleys of consecutive days of no retching in between. The peak retching scores increased slowly over the first 2 months of the study and then dropped slightly in the last months of the study. The pattern of her evening retching frequency was very similar. She began the study with infrequent low peaks over the first month of the study, which slowly increased in intensity through the second month of the study, and then dropped off slightly during the third month of the study.

Abby’s bother by retching scores range from 1 through 4.5, with a mean bother of 1.39. Her mean evening bother by retching scores were higher than were her morning scores. The pattern that develops in her bother by retching scores (Figure 17) showed no bother by retching throughout the first month of the study. During the last 2 months of the study, Abby’s bother increased in intensity and she had a lot of variability in her scores.

Salivary cortisol.

Figure 18 shows Abby’s morning and evening salivary cortisol values across the 85 days in which she participated in the study. This pattern showed higher peaks and higher valleys in the first 50 days of the study as compared to the remaining 35 days. Figure 19 shows the difference between Abby’s morning and evening cortisol levels. There was some evidence of the classic diurnal pattern of cortisol excretion, with higher levels in the morning and a decrease in the evening, but this is not consistently shown in these figures.
Figure 16. Abby’s AM and PM frequency of retching over time.
Figure 17. Abby's AM and PM bother by retching over time.
Figure 18. Abby's AM and PM salivary cortisol levels over time.
Figure 19. Difference between Abby's AM and PM salivary cortisol levels over time.
There did not appear to be a strong gradient effect from morning to evening. There was only some evidence of this effect, thus supporting the notion that while Abby was undergoing treatment for chemotherapy she experienced cortisol excretion patterns that did not suggest she was in homeostasis.

Figure 20 shows Abby's morning and evening salivary cortisol levels in the categories of day since chemotherapy administration. In the morning, Abby's cortisol peaked at Day 4, dropped down for 2 days, and then peaked again at Days 7 and 8. This pattern of cortisol levels, over her chemotherapy cycle, shows high variability. Abby's evening cortisol levels peaked on Day 10 but were similarly high on multiple days across the cycle.

In conclusion, Abby's cortisol secretion did not appear to be controlled by the classic circadian rhythm that characterizes homeostasis. She had a pattern of high variability that lacked any clear trends and did not show a gradient effect over the course of a day. This finding may suggest that the stress that Abby experienced as a result of treatment is being manifested physiologically by her body excreting higher levels in response to differing levels of stress throughout the day. Thus, in trying to maintain a state of homeostasis, her body continues to excrete cortisol into the evening hours when it should be dropping off.

Sleep.

Abby's sleep efficiency scores ranged from a low of 30.0% efficient to a high of 88.6% efficient. She had a mean sleep efficiency score of 69.1%, showing that of the total amount of time she spent in bed trying to sleep, approximately one third of the time was spent not sleeping. According to this data, Abby was a moderately efficient sleeper and was able to sleep for periods long enough for her to experience deeper levels of restorative sleep.
Figure 20. Abby’s AM and PM salivary cortisol levels by day since treatment administration.
This finding is important in light of Abby’s interview data, in which she described very high levels of difficulty with sleep across her time in the study. Figure 21 shows Abby’s sleep efficiency scores over the course of the study, with a pattern of high variability.

**Anxiety.**

Abby completed the Revised Children’s Manifest Anxiety scale once each month while in the study. Her total anxiety score (Table 5) increased drastically from the first testing to the second testing. The third testing showed a similar level of anxiety. These scores are standardized based on matched age and race normative samples. For the total scale score, the population norm has a mean of 50 and standard deviation of 10. Thus, any score greater than 60 indicates a child is having difficulty with total anxiety. The three subscales, physiological anxiety, worry/oversensitivity, and social concerns/concentration, have a normative mean of 10 and standard deviation of 3. Thus, any standard score greater than 13 indicates a child may be having a difficulty on a particular subscale.

<table>
<thead>
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<td><strong>Scores on the Revised Children’s Manifest Anxiety Scale Over Time</strong></td>
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<tr>
<td>Worry/Oversensitivity</td>
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<tr>
<td>Social concerns/concentration</td>
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** scores falling more than one standard deviation above the norms

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Figure 21. Abby’s Sleep efficiency over time.
Abby's total anxiety score in the second month of the study is high enough to warrant concern. This finding is in concordance with the development of anxiety that Abby described in her qualitative data. Abby's scores on the subscale Physiological Anxiety also fell more than one standard deviation above the normative mean for her age group. This subscale is an index of the level of physical manifestations of anxiety. A high score indicates she was experiencing certain symptoms that are typically experienced during anxiety, such as sleep difficulties, nausea, and fatigue (Reynolds & Richmond, 1990). From these data, it is difficult to ascertain whether this scale assessed her anxiety regarding her experience with these symptoms or more basically the incidence of these symptoms.

Summary of Self-Report and Biobehavioral Data

According to the self-report and biobehavioral data, the symptom patterns associated with Abby's experience with pain, fatigue, nausea, and vomiting were fairly intense throughout the study. She appeared to have no relief from nor was she able to develop the ability to habituate to these symptoms as time passed. While living with these symptoms on a daily basis she also experienced high levels of variability in their appearance. These symptoms would fluctuate daily from high levels to more moderate levels with no apparent trends across time. This indicates, that it may have been difficult for Abby to anticipate when she would experience a particular symptom and how long it would last. Indeed, the symptom story told in her qualitative data concurs with this finding. Abby did not appear to be particularly bothered by worry or sleep alterations.

Abby's Interview Data

Abby was interviewed at four different points in time over the course of the study. She was very articulate and an excellent informant regarding her experiences with
chemotherapy. She appeared to enjoy our time spent in the interviews. A unique factor of Abby’s treatment was that she was receiving her treatments through the outpatient clinic. She would spend every second Thursday in this clinic and then would return home with symptom control medications for her family to administer. Abby did not spend one day hospitalized. In addition, because of her family’s recent relocation, Abby had not yet started at her new school. In light of the diagnosis and treatment it was decided that she would be receive her education at her home with tutors.

The first interview with Abby was conducted at Treatment Day and Study Participation Day 13. This date was chosen as the first interview date so as to give Abby a period of introduction into the study and, as the symptom diary was to be used as an elicitation device, time to get involved in filling out of the daily symptom diary. This allowed her to get a sense of the type of information and experience that I was interested in. This date was also chosen so as to be far enough following her first cycle of chemotherapy for her to have had a chance to reflect upon the symptoms produced by the first cycle, while not in midst of the theoretically most intense symptom period. The next two interview dates were chosen so as to vary the window in time based upon proximity to chemotherapy cycle administration and number of cycles between interviews. Thus, Interview 2 was conducted 2 days following two consecutive cycles and 11 days prior to the next cycle. Interview 3 was conducted 8 days following one cycle of chemotherapy and 5 days prior to the next cycle. Interview 4 was conducted on Abby’s last day of her participation in the study, 13 days following two consecutive cycles, and 1 day prior to the next cycle. Again, these times were chosen to capture such variations as potentially feeling very intense symptoms versus feeling very mild symptoms.
Following the second reading of the transcribed audiotapes from Abby’s interviews, I began to assign codes to the data, based upon the symptoms that she talked about, such as nausea, pain, and sleep alterations. Thus, I searched the transcribed data line by line looking for citations of symptoms. However, I realized that by analyzing the data at this level, I was missing an important feature of Abby’s symptom experience. Abby organized her discussions of her symptoms by placing them in a more abstract framework. This framework seemed to be based upon the effects that the symptoms were having on her ability to cope on a daily basis. She would use specific concepts, such as worry, anxiety, and depression, repeatedly to describe the impact of various symptom. For example, Abby’s talk about pain was firmly rooted in her discussion of how much worry the pain was causing her on any particular day. When I would ask her specific probing questions regarding the pain, again see would pull away from describing the actual pain sensation, to details regarding how the pain was affecting her levels of worry. In addition, the concepts within this larger framework, either totally changed or were transformed over time. For example, her talk about pain while rooted in worry during the first interview became rooted in anxiety in the second interview.

Therefore, I present the analysis of Abby’s qualitative data chronologically based upon interview and treatment dates. This presentation begins with an illustration of the organizing framework that she used to discuss her symptom experience, the concepts that were embedded in this framework, and how these concepts changed over the course of the study. The presentation will then identify the individual or combinations of symptoms that were discussed at each specific point in time in the framework. Please see Appendix C for illustrations of the organizing framework used in this analysis.
Interview #1: Treatment Day 13

The first organizing concept Abby used to discuss her symptom experience was worry. Very early in the interview, she began talking about worry and how all of her early symptoms were related to levels of worry. Her descriptions of worry can be separated into three main areas: worry about symptoms of illness, worry about symptoms of treatment, and worry about the unpredictability of her symptoms.

**Worry about symptoms of illness—prediagnosis.**

Abby separated her worry about symptoms of illness into those that occurred prior to her diagnosis of Hodgkin’s Lymphoma and those symptoms of illness that occurred following her diagnosis. She described her worry about prediagnosis pain:

> It was painful while it was growing. And then it wasn’t painful anymore. And I remembered someone had told me, “If it’s painful, it can be an infection. And if it’s not painful, it could be, it’s a tumor of course.” So I said “Well, yeah, it’s painful,” because I didn’t want to think about it then.

Abby’s feelings of worry that began prior to diagnosis were in reference to several specific symptoms she was having. She began to experience arm and chest pain, fatigue, headaches, and night sweats. While fatigue, headaches, and night sweats seemed more in the realm of ordinary young adolescent experiences, the appearance of the pain in her arm and chest alerted her to a real problem.

A very interesting finding regarding worry in the prediagnosis phase was a concept that Abby called her “analyzation.” The analyzation entailed information she had obtained from multiple sources, such as the media, relatives, friends, and others, that a lump was only cancerous if it was not painful. If a lump was painful then it was most likely “an infection, or
cat scratch fever or something.” Thus Abby’s worry or anxiety, an important symptom involved with the illness and the treatment, was really dependent upon another central symptom, pain. She described this analyzation at several different points in time during the first interview. Because of her understanding of the importance of pain to the eventual diagnosis of a malignancy, she vacillated between deciding upon whether her tumor was painful or painless. In addition, the data also suggested to me that although she understood this “analyzation” was important and valid, it confused her and she did not really put all of her faith in it.

Abby’s worry during this prediagnosis phase seemed to be based upon what the lump would really be about. She worried when the lump brought about pain and when she did not feel any pain. She worried about the rate at which the lump was growing. She described some of her worry during this time period by saying, “... then I started getting, kind of worrying, because between the time that it was growing, it had gotten bigger, and then I noticed another one coming up right above it.”

Pain was a central prediagnosis symptom that Abby experienced. The pain was most often based upon the lump in her leg, but she also experienced pain in her chest and arm. Pain was a constant source of worry for Abby.

One of Abby’s earliest symptoms of her illness was alterations in her sleep patterns. She felt that, even though she seemed to be sleeping throughout the night, she was not sleeping well. She knew she was not sleeping well because she felt so tired throughout the day and would fall asleep in class.
Abby’s experience with fatigue began in this prediagnostic stage. She felt tired all the time. She was falling asleep during class and her teachers were beginning to feel concerned, as this was not her nature. She felt that she did not have the energy she previously had.

One of the symptoms, in addition to arm pain, that caused the most worry for Abby was dyspnea and pain in her chest or lungs. She described:

I’d go to school and if anybody made me laugh, it would hurt real, real bad. And shortness of breath. I started having trouble breathing to where I’d have to hold my breath just to lay down and wait and start breathing again.

Worry about symptoms of illness-post-diagnosis.

Much of Abby’s worry post-diagnosis was centered around her mortality. Her initial reaction to her diagnosis was “there was a thought in my head, but I didn’t really. really believe it, that there was a possibility I could die because in a lot of cases cancer brings death.” Her post-diagnosis worry about individual symptoms became much more specific and focused. She described how her worry about pain brought about other worries or thoughts regarding her ability to fight the cancer:

... because the pain was just a small part of it, I mean, the pain was a big part of it. but compared to the cancer and all that and what it does to your body, it’s just a little thing. It’s just a little thing and I’m thinking, if I can’t conquer this, how am I going to conquer a cancer?

It was at this stage, prior to the commencement of treatment, or any knowledge of the type of treatment she would receive, that Abby first began to worry about losing her hair and the effect this would have on her ability to make friends at her new school. She described these worries:
And school. I was about to start school. I was supposed to start school that day, and I wasn’t going to be able to go to school and thinking about how I probably wouldn’t be able to make friends right away because, um, like, who’s going to want to talk to a girl that doesn’t have hair and real sick and, you know, never really being able to do some things and a girl who’s basically gonna live like in a bubble. I worried about all those, that, it all ran into my head real fast.

Worry about symptoms of treatment.

In this first interview, Abby began to describe some of the symptoms she had experienced as a result of her first cycle of chemotherapy. Once again, her descriptions of these symptoms, at this point in time, were rooted in the amount or intensity of worry they were causing her. Her worries during this period were related to multiple symptoms and feelings but mainly focused on her anticipation of how severe her symptoms would be with her next cycle. She was always looking ahead, attempting to forecast, based upon the current cycle, how she would feel with the next cycle. She described some of the more general worry:

After we started the first treatment and I felt fine the day after, I thought, “Well, this is going to be a breeze. If I’m feeling fine today, then this is going to be okay.” But then I got sick, and then while I was sick, I was very, very worried. I was really scared because I had never been sick like that before, never. I couldn’t sleep, and I remember I told my mom one night while I was trying to sleep and I was real ill that I really thought I was dying. And I wasn’t afraid for myself dying but I was afraid of, like, the aftermath for them.

... I don’t want to get sick again. I’m very, I’m a little bit nervous about that because I really, I don’t know how I’m gonna to be able to handle that again.
Abby was very worried and anxious about the effect her first cycle of chemotherapy had on her. She felt that her body was falling apart. She experienced a lot of pain following the first cycle and worried that if she could not handle the pain after one cycle how she would endure multiple symptoms after multiple cycles. Along the same lines, she felt that if she was falling apart in reaction to the treatment and could not endure the treatment, she wondered how she would fight the cancer.

Abby was disconcerted by the treatment and the effect it was having on her body. This disconcertion dealt with the idea that the treatment was supposed to cure her, but she felt as though it was killing her.

Well, it's a feeling that I had for a while with this. It didn't seem right. It just didn't make any sense to me that for my body to get better, I have to completely break it down and get sick and just, and just so I could get better. It just didn't seem right.

Abby was also worried and perseverated on specific symptoms such as hair loss, pain, sleep alterations, and nausea. She searched for some control over when the symptoms would be coming, how bad they would be, and how long each would last. She described her questions about hair loss:

... um, it was bad at first. It was one of my main worries. I wasn't even thinking about getting sick, I was thinking about losing my hair. But I was really worried also because they said that, like I said before, my, a big worry of it was losing my hair. And I was worried, well, when is it going to start falling out? And I worry, that, that was just another big worry, but it's just gotten very small now. Especially when I got sick, and I'm thinking, "Okay, which would I rather be, like this or not have hair?"

Whew! Not have hair."
Abby experienced drastic alterations in her sleep habits following her first cycle of chemotherapy. She had trouble falling asleep and, once she was able to sleep, she had frequent wake ups. She no longer felt comfortable, or safe, sleeping alone and would have a family member sleep with her each night. She described this change in her sleep habits:

She (mom) had to lay in with me every night just so that I could try and get any sleep. And I didn’t want to keep her up all night. And I’d go and lay in another bed and I’d do everything, try to rock myself to sleep, doing everything I could possibly do, taking my own medications, eating and drinking, trying to do everything, and it wasn’t going away. And it was horrible.

Abby’s first experience with pain following the diagnosis came from the surgical incision site. For approximately 1 week following surgery to remove the tumor, Abby experienced sharp, stabbing pain at the surgical site. She found it difficult to walk around, making dealing with the diagnosis and pending chemotherapy treatment even more difficult. Her pain related to treatment continued to be quite intense. Her inability to find relief from the pain, and the worry that came with the pain, took on a larger meaning for Abby:

... but it couldn’t take the pain away. And there was nothing. I couldn’t lay down, my body was so sore, and if I laid down, I couldn’t lay this way, I couldn’t lay that way. I couldn’t win. And because I couldn’t win with the pain, I didn’t feel like I could win against the entire cancer thing.

Another treatment symptom Abby described in detail was the loss of her hair. When Abby was first enrolled into the study, she had long blond hair that she wore straight down her back. When I first met her and was enrolling her into the study, I asked her if she had any questions for me. The only question she had was if I could tell her with any certainty whether
she would lose her hair. She felt that the oncology team was not giving her a straight yes or no answer regarding her hair loss. Abby felt that she could deal with it better if she knew for certain that it was going to fall out. Thus, she was struggling with the anticipation of this symptom long before it actually occurred. By the time the first strands began to fall out, she seemed ready for them. Over time, I could see the positive transformation that occurred as a result of Abby’s thinking about this symptom early on in her treatment. This was the only symptom Abby experienced in which she benefited from thinking through her response prior to it happening. Here are some examples of her early, pre-hair loss thoughts:

   But I was really worried also because they said that, like I said before, my, a big worry of it was losing my hair. And I was worried, well, when is it going to start falling out? I noticed he said that it takes about 10 to 15 days to start, and I noticed that when I combed my hair, a little bit comes out, like a couple of strands here and there. More more than normal. But it’s not a big deal. Now I’m just like waiting for it to fall out. Just get it over with so I can go get those cute hats. And then I can just throw them on. My attitude about losing hair has been a lot better. I’m really proud of myself for that one because, um, it was bad at first. It was one of my main worries. I wasn’t even thinking about getting sick, I was thinking about losing my hair.

In her first interview, Abby spent a lot of time describing her response to the symptoms she was experiencing. This response was in the form of worry. She was surprised and horrified at how she felt physically and emotionally and was frightened by her response. She felt frustrated that even though her family and friends were very supportive they did not truly understand how she was feeling, and at times she felt they made light of her suffering. She described how her family’s support made her feel:
My mother would try and comfort me and tell me that things would be okay. But.... but you know, she didn’t really know how I was feeling. No one could understand how that felt so, it was... It was about, you know, I don’t think that, I don’t know what would have comforted, I don’t think anything could have really comforted me out of that.

... And I’d go and lay in another bed and I’d do everything, try to rock myself to sleep, doing everything I could possibly do, taking my own medications, eating and drinking, trying to do everything, and it wasn’t going away. And it was horrible. It was non-stop, laying in the room in the daytime with the windows closed with the blinds down and all light blocked out, and I couldn’t get out of bed, and I felt awful. And when I talked to my friend, I just broke down, “I don’t want to live like this.”

And she was, “You have to do this. You have to do this, (Abby). You cannot, you can’t give up on this.”

Abby seemed to feel that she had been tricked. She was expecting to feel bad and then when she felt okay for a few days following the chemotherapy administration she was happy and relieved. But then the symptoms came on strong and took her by surprise:

So, I was kind of like expecting the worst, but when it didn’t get bad the day after, I was just, “I’m gonna be okay, then.” And then, tables turned, and they were like, “No, we were just kidding. You’re only okay for a little while. But you’re gonna have to go through it now. Yeah, they were just like, “Oh, we’ll give you a good day, but then you’re going to have about five really bad ones.”
I asked Abby what she felt would be the most important information she could pass on to other teenagers about to begin treatment. She responded by describing the unpredictability of the symptom response:

Yeah, that it’s unpredictable. It’s just, you know can’t say that you’re gonna be fine the first, just because you feel good the next day doesn’t mean that two days down the line you’re gonna feel really, really bad.. Um, I didn’t, cause I really didn’t expect that, I thought that if you got sick, it was going to be right after the chemo, it was going to be right then and there.

Interview #2: Treatment Day 31

The second interview was conducted at Treatment Day and study participation Day 31. In the period between Interview 1 and Interview 2, Abby had received two more cycles of chemotherapy. The interview was conducted 2 days following her third cycle of chemotherapy and 11 days prior to her fourth cycle. The main organizing concepts, under which Abby described her symptom experience in this interview, as seen in Appendix C, were threefold: (a) symptoms of cancer versus symptoms of treatment, (b) worry transformed into anxiety, and (c) comparing cycles of chemotherapy.

Symptoms of cancer versus symptoms of illness.

As in the previous interview a major concept for Abby in this interview was the difference between having cancer and getting treatment for cancer. Abby was confused by the notion that things were not so bad for her when she had cancer. Her problems began once she started the treatment. Abby thought it was illogical that to get well or get cured she had to be made so sick. Abby described how contradictory this felt to her:
... Just how it’s not fair. Because I just didn’t, it, because I, and then I would keep thinking, maybe if I didn’t get treated, if I didn’t have to go through chemotherapy. I would be fine right now because when I just had just cancer and I didn’t even know I had it, I was fine. I had a little. I had few symptoms, but they weren’t all together. It was like just one after another, kind of secretly coming on, and I wouldn’t really think about it, what they were all coming from. And, but health-wise, I felt fine. just really tired all the time, and that was something I got used to. And, um. I wasn’t sick like I am now, and I just kept thinking, what if I didn’t get the treatment, I would be fine.

Worry transformed into anxiety.

One of the new responses she described in this interview was high levels of anxiety that occurred when her symptoms became unbearable. I asked her to talk about the anxiety. Her anxiety seemed to be a response to the loss of control regarding her physical symptoms. The lack of predictability of her symptoms was also anxiety provoking. She described it:

... it was just so frustrating that I couldn’t, there’s nothing I could do to get rid of this. There’s nothing I could do. It was not in my hands at all, and that was just so aggravating. And knowing that, um, I had just spent a couple days of feeling great. and after the first chemo my sickness only lasted a few days and then I felt wonderful. I was back to normal. And then it was just so aggravating to think that, you know. I had to go through this again, and knowing that after the, before the first chemo I was fine, I was fine before any treatment started, and then treatment starts, and I feel fine for a couple of days, then I get incredibly sick, more sick than I’ve ever been before. then I start feeling good again, then I go for another chemo, and it just all starts over again. And that really bothered me.
The transformation of worry into anxiety brought with it behavioral manifestations. One of the most visible behavioral manifestations of her rising anxiety was body rocking. She would sit by herself and physically rock her body back and forth. This rocking seemed to be the only action that brought her any comfort. Her parents and family were disturbed by this manifestation. Abby described the rocking and how it helped her:

Nobody could tell me that the next day was going to be better, and I kept wanting to, and whenever I get sick like that, I can’t help it. I’d just always have to ask like my dad, “Do you think this is going to go away tomorrow?” Just, I wanted somebody to just tell me, “When you wake up tomorrow, if you rest tonight, you really will feel better tomorrow and this will go away.” And I knew that if I really worked hard on resting that night, that it would really pay off. But every time I’d ask him, he’d go, “I don’t know.” And I’m just, “Oh, come on. Just somebody know.” So one night when it got really bad, it was the night that actually my dad had to run out to go get the pain killer because it got this bad. It was before he came home from work, my mom had to go pick up my brother from school and my sister from work, and so I knew she was going to gone for awhile, but I felt fine enough to where she could go, so I told her to go ahead. And I was up in her room watching TV and I just got really, really anxious, and I didn’t want to be alone. So I called my dad and talked to him on the phone, and he was trying to get off work early to come home to me, like an hour early. I kept telling him, “Don’t worry about it. Don’t worry about it.” But he knew that I was really, really having a hard time. And I just started rocking really hard, back and forth, and he kept telling me, “Don’t rock. You’re just going to upset your stomach.” But there was nothing, I just couldn’t help it. It became, like instinct, every time I started
feeling bad, I'd start rocking whether wanted to or not. It wasn’t something that I just decided, “Oh, let me start rocking.” It was just doing it without even thinking. I got really aggravated, and I tried to play it off like I was okay, on the phone with him. And I came down here, and I just sat on the couch, and I rocked. And for about 45 minutes I just sat there and rocked, and I cried and cried and cried.

... It just kind of kept me from, I don’t know. I felt very bad anxiety, and the rocking was just kind of like soothing, like emotionally and mentally it was soothing because it was something that kept me busy, something to keep my mind off of the pain, to just concentrate on the motion of going back and forth or, and if I couldn’t rock because it was upsetting my stomach, I’d start shaking my foot or my hand. Just something to do to keep my body concentrated on something else.

A second behavioral manifestation of Abby’s increasing anxiety was related to alterations in her sleep habits. At night, Abby would not sleep alone. I asked her why she felt this need to not be alone. She explained:

... I guess because I’m afraid of getting really sick at night. And, maybe not being able to get out of bed to go let them know that I’m really sick. Or, I guess just knowing that when, because when I can’t sleep I wake up a lot in the middle of the night. And my mom knows when I wake up, so she kind of wakes up with me, and she’ll just kind of soothe me back to sleep. Even though I don’t like bothering them. I try not to even if, even now when I can’t sleep at night and I’m sleeping in their room. I just kind of wake up, and I know that they’re there, and I just kind of lay there for a little while and usually put myself back to sleep. I don’t like to bother them, but I find myself always wanting to be by my parents now. I guess, I don’t know what it is. I
guess it's just like an emotional thing. Like being really close. I've gotten really close to them. It's a big comfort. Because, you know, like when, you know, you're little and you're used to your mom comforting you and taking everything away. It's kind of like I feel like I'm just really little again, and I just really feel like it helps a lot. It does.

While worry was not as central a theme in this interview as it had been in the previous interview, Abby talked about the link between her worry levels and the accompanying symptoms. In this interview, she made a clear connection between trying to have a positive attitude and worry. This interview also contained data on the development of anticipatory symptoms. Abby's experience with her symptoms following the first, second, and third cycles of chemotherapy was so intense, inescapable, and relentless that she would sit and wait for them to arrive once again. This waiting and thinking about the imminent nature of her symptoms caused much anxiety and worry. She described this feeling:

... because every time I feel really down or if I worry about something, I usually come down with whatever it is that I worry about. Because I'm just thinking, like if I. um, like, let's see, if I think that I'm really gonna get sick, and I feel that I'm. I can feel it coming on, and I worry about it all the time, it brings it on. And I get sick, and then I'm like, "Oh, great. Now look what I've done." I should have stayed positive. but I don't know, I think your body has like a way of telling you what's coming anyways, and you just sit there and you worry about it, and you feel it. Instead of thinking, "No, it's not gonna come. I'm not gonna let it come. And I'm just gonna be careful and keep myself healthy." I sit there and I'll, sometimes I'll go, "Oh, gosh, I really don't want that coming back." Or I'll sit there and worry, "What can I do to keep this from coming back?" And it just drives me crazy worrying. It just does
because I remember how it feels. And it’s not like I can get it. feel better, and forget
what the feeling was. I can still remember the feeling. I can still remember everything
about it, and how I was feeling mentally and physically, so, and I don’t want it. So I
sit there and I worry. I’m thinking, “No, I don’t want to go outside today because I
don’t want to get very ill tomorrow. And I don’t want to go here, and my sister’s
always saying, “You need to get out of bed. You need to get out of the room. And we
need to go shopping.” And I’m just so afraid of going there and using all my energy
and catching something and then getting sick. So some days, it’s just days that I
isolate myself. I won’t even go outside to get the mail because I’m so afraid.

This burgeoning process of anticipating her symptoms brought about a sense of dread
regarding each pending cycle of chemotherapy. Abby described this dread:

I get to the point where I don’t even want to get it anymore, and I’ve only just started.
Because, um, Dr. Rosen said something about um, how my counts got really low. at
first after that second chemo, and that usually doesn’t happen until after the fourth
treatment or so. And I was thinking, “Well, what is wrong with me for this to happen
so soon?” I just don’t, a lot of times I just don’t want to get them anymore. I hate the
fact that I have to go in and um, the feeling that I get while I’m there. It’s just this
really nauseous feeling and it’s a very groggy, groggy feeling. I slept through the last
two chemos. But when I wake back up I’m just so “ugh,” and I just want to get out of
there, and thinking about it after that, when I’m, especially when I’m sick, just makes
me even worse. And I don’t want to go back because it’s the thought of knowing that
I go in to get better, but a couple of days after that, I’m not getting better. I’m getting
worse. And to know that just to get back to my good health I have to go through all this stuff, it’s so aggravating.

Comparing cycles of chemotherapy.

One of the main organizing concepts Abby began using to describe her symptom experience during this interview was to compare how she felt her symptom experience had changed after each cycle of chemotherapy. Abby was very clear in describing how her response to her treatment was changing:

... When I first started chemo it wasn’t quite as bad. I didn’t really exactly know what was to be expected. I knew that kids get really sick when they get chemo, but I never really expected for me to get really bad off. And after that first chemo, I got really, really sick, and um, we had changed a couple of medications to keep me from getting certain symptoms, like my head was swelling and, that was really, really painful. It was like an allergic reaction to one of the steroids for my lungs. And after I got taken off of that, I didn’t think I’d really get that badly sick. I thought that it was all just because it was just an allergic reaction, the second time won’t be bad. And then the second time came around and I got pretty sick.

... The second chemo wasn’t worse, but it was bad. The first time it was like having a migraine like every day, every night. Nothing could help possibly. And I couldn’t sleep. And then my body was really sore, so I couldn’t sleep because I couldn’t get comfortable. And then just the anxiety of not being able to sleep, it just puts more stress on your body and on your mind, and those days that I had to go through after the first chemo were really, really bad. It was, I couldn’t have like, light in my eyes. I had to stay in a really dark room, and I didn’t want to get out of bed.
because it was just like the worst pain in my head. And the nausea was really bad, and um, just, just, and the body pain was really bad. And that took about 4 or 5 days to go away. And then after that I was feeling much better. I was all energized, and I went back for chemo again and, for my second chemo, and I was feeling fine after that. and I was like, “Oh. this isn’t so bad.” Well, they started me on the Neupogen because my counts were so low, and then that made severe bone pain, it was just the worst. And my arms were really sore. Some days I couldn’t even use my arms. And, like, whenever my mom would bring me soup, I couldn’t hold the bowl because my arms would get so weak and so sore. My legs started to really hurt. And I couldn’t sleep at night because of the pain, and I couldn’t get rid of it. So really the first chemo and the second chemo were both bad but for different reasons. And I didn’t sleep the first time either, but if I had to choose, I’d pick the second one over the first because of the pain in my head was the worst. But the second time around I didn’t really think was quite as bad as the first time except it lasted longer. It wasn’t like 4 or 5 days, it took about 6 days or so. And the bone pain, it felt like it was muscle soreness at first, so I’d get my dad like to rub it out, and it wasn’t helping. It was so deep, and it was annoying. Really annoying. So it made me very, very aggravated and from not sleeping, I think emotionally I did worse the second time around. I started this thing where I started rocking myself, and I’d rock back and forth and sideways.

Abby’s change in sleep patterns was another extreme source of distress for her. Her inability to sleep was closely tied to the intensity of other symptoms such as pain. Abby continued her need to sleep with a family member in her bed. Abby talked at length about her alterations in sleep:
... The lack of sleep, that’s the worst thing. Because it makes everything worse. Emotionally, when I can’t sleep, I get so aggravated, and my anxiety gets so bad because I just want to sleep so bad, and I can’t. There’s nothing in the world that helps me. Not one thing that helps me to sleep when I can’t sleep like that. And the next days, I keep thinking, all I can think about, “I hope I can sleep tonight.” Because I know when I can sleep at night, I feel a lot better. But there’s not one thing that could, like, really reassure me that I was going to sleep better that night and that I was going to feel better because I slept. Or if I did fall asleep, how much sleep I would get. and there’s nothing that could really reassure that.

Closely related to Abby’s problems with sleep was the extreme fatigue that she felt consistently throughout the study. Although this was a very intense symptom, it did not seem to carry with it the bother that some of the other symptoms had. She described her fatigue:

... my energy level. It’s been down, real down. Actually, but in the beginning of the week when I was feeling better. I was taking walks on the trail, and that took a lot of energy, but it was really nice to get fresh air. Normally just walking up a little bit of the hill I was winded completely. I find that, like especially, like this is the first time I’ve come downstairs today. I can’t really get down the stairs or up the stairs quite as easily as usual because I get so tired I usually have to stop midway or at the top or something. And that kind of gets me a little bit down, “Can’t even make it up the stairs. Come on, (Abby)!” You know like you just, I want to just like boost myself up there but sometimes I need my dad to help me up. So I just kind of, like when I’m feeling really sick like I was yesterday and today, I stay up in bed and I get up, though. and I’ll walk around upstairs just kind of like keep, not staying in one place . And um.
but I didn't come downstairs last night, and um, when I am downstairs it just takes me forever to get back upstairs because I wait for my energy level to high enough to where I can walk up the stairs, but I get dizzy when I walk up the stairs, too. But I'm getting used to it. It's not really so bad. At first it was like, just being tired all the time. I was kind of used to not be very energized like usual because before I even got treated I was tired just naturally from the cancer, I mean I was just really tired, but not like this, not like, and my mind was always tired. And my body, but not quite as tired. but now it's just like my body just feels like it's sleeping all the time, or it's trying to sleep. And then, especially when I can't sleep, it gets even more tired, and I get more weak, and my mind gets more tired.

When Abby did not spontaneously begin to talk about nausea, I asked her about it. As with the first interview, she discussed how the nausea did not seem to bother her as much as the other symptoms, such as pain, sleep alterations, anxiety, and worry. However, some of the interview data contradicted this statement and it seemed that much of her anxiety was related to nausea. For example, Abby described her nausea:

... Usually when I get the nausea, it's with other really bad symptoms, so it's not quite as bad. I really don't really bother with it quite as much because I try to like, like yesterday, I had a really sore throat, and I was really nauseous, and I was getting a little bit of a headache, and I was so worried about getting sick again like the first time with my headache and my throat pain and my muscle pain. I was really worried about that, so I tried to pay no attention to the nausea. And, it seemed that I was acting out more on the nausea more than anything else because I sat here and I kept thinking if I drink this hot soup and I eat it all, it will help my throat. It'll soothe it. And not
only that, it’ll be good to have some fluids and some food in my stomach. So I tried to force myself to eat that, but I wasn’t really paying attention to the fact that I was really too nauseous to eat something like that at the time. So I ate a couple bites, and I was like “Ooo, my stomach’s not agreeing, but it’s making my throat feel better. I’ll have a couple more. And I put it away, and then I went to sleep. And as soon as I woke up, it all came back.

... So I didn’t try to force myself when I’d get really nauseous. but I basically, whenever I got really nauseous, I’d just kind of sleep it off. But there are days when I can’t sleep, so um, that’s when the nausea will really bother me, and I’ll just have. I find that eating toast really helps my nausea.

Interview #3: Treatment Day 52

The third interview was conducted at Treatment Day and study participation Day 52. In the period between Interview 2 and Interview 3, Abby had received one more cycle of chemotherapy. The interview was conducted 9 days following her fourth cycle of chemotherapy and 5 days prior to her fifth cycle. The main organizing concepts, under which Abby described her symptom experience in this interview, as seen in Appendix C, had four components: (a) anticipatory anxiety, (b) unpredictability of symptoms, (c) cascade of symptoms, and (d) comparing cycles.

Anticipatory anxiety.

Abby’s inability to stop thinking and worry about her symptoms came in the form of anticipating how the symptoms would present themselves following the next cycle. At this point in her treatment cycle, her anticipation and anxiety were strong enough to cause a
physical response to her thoughts. Thus, if she was thinking about the clinic, she would remember the smells, and the smells would cause her to vomit.

The symptoms haven’t gotten worse, but the way I react is getting worse because it’s been going on. . . . I feel like inside it’s been going on long enough and I know how much more I have. I have a lot more. And it’s just . . . I just wish I could . . . like just a couple days, just be like, I don’t have cancer, I’m not going through chemo. And with those little bit of symptoms now, my patience getting smaller and smaller. it’s really bad still for me.

Whereas the infusions themselves brought about nausea and vomiting, just thinking about getting chemotherapy also had a similar effect on her, which evidenced further development of Abby’s severe anticipatory nausea and vomiting. She described it as:

If I can’t throw up and I’m retching, I think about chemo and that helps it come up. It really does. Because sometimes I’m just there and I’m like, it’s just right there and it’s ready to come up but you just can’t get it out and I’m thinking, now what about that lovely . . . when they’re trying to flush your port and you get that taste in your mouth. Ooh, and then it all comes out for you.

In this interview, Abby wanted to let me know that she felt that her response to the symptoms was worsening. She was very frightened by the mounting anxiety, as she felt she could not control her own response. She focused on her increasing anxiety levels in response to the symptoms and to the depression, isolation, and loneliness she felt was setting in. The isolation Abby was experiencing resulted from her being unable to leave the house very often and from the notion that no one really understood how she was feeling. She expressed
concern that, because of the anxiety, loneliness, and depression, she would not be able to continue with her treatments.

... if something doesn't feel right inside. Like if my stomach started to hurt, then I wouldn't be able to breath or catch my breath. And then I feel really depressed and I feel like I just want to cry or scream or kick or shout or ... I'm just tired of this, I want it to be over. I'm so sick and tired of this and I get to the point where it's just like, I do not want this anymore. If it has to be like this, this is not fair and I just start getting really, really depressed and then something clicked and I went into a major anxiety attack. I mean I was screaming, I was crying, I was punching walls. I was kicking walls. I was walking all upstairs pacing the hallway, going through every room hitting stuff, knocking things over. Just really on a rampage. And my little brother got really scared 'cause he didn't know what was going on. So he started crying and he came upstairs. And when I saw him crying I kind of calmed down and I went and just hugged him and I was rocking and he was rocking with me. He's like, what is going on here, because I was holding him and rocking and I was saying, Gregory, I'm sorry I don't know what's wrong, what's going on? I said, well sometimes I just get really angry and I get really anxious and I tried to explain it to him. And he was saying, well hit this pillow, hit this pillow. And I was like, I've already let it out. I have no energy, I wore myself out. So I laid down with him and he was all worried. He said, let me call Mom. I said don't call Mom, don't worry her. And so my Mom came home with my sister and Gregory went down there and told them, Abby was really upset, she was screaming. She was saying all kinds of stuff and just screaming at the top of her lungs and crying and beating stuff and just... My
mom came upstairs and she said, what’s wrong? And then I just started crying and I must have cried all night long. I mean it was just constant crying and all I wanted to do was cry. Because it was helping me feel better and . . . I guess that I really didn’t realize how hard it was gonna be. And now I know exactly how hard it is and that this is not over. And it’s like . . . my Dad tells me, oh you’re a third of the way done. I’m like, this isn’t even half way done yet.

One of the big differences between this interview and Abby’s first two interviews was the almost complete absence of her use of the word “worry.” Even though she was still writing about worry in her daily diary, she was not reporting any worry on the Likert-scale measure and she rarely mentioned the word in this interview. When the interview was almost over, I asked her about her worry. Her response made it clear that her worry was usually associated with anticipation of the symptoms that followed a cycle of chemotherapy.

Abby had spontaneously used the word depression or feeling depressed as a response to the symptoms brought on by her treatment. I asked her to describe what she meant by this in more detail. She replied:

……I just don’t feel quite as optimistic and happy as usual. I just want to … every day I have to cry. I just have to lay down and cry and whether or not I’m suffering, I just feel really sad. I do. And I know I try to … I don’t ever admit it to my parents, but I think I do try to hide it sometimes cause I don’t want them to know, but I have never really been a person to let any kind of depression inside, but I have been very depressed lately. And I’ve just … I feel at my lowest.
I then asked her if she could tell me when she thinks that the depressed mood started as well as how severe she thought her depressed feelings were. She replied:

I think it's always been there but it's just really started to show itself. I think my third chemo. See the anxiety and the depression are really actually two different things inside. It's just . . . I do have a very optimistic way of looking at things. I know I do. And I have very high hopes for some stuff and I'm actually a very . . . I'm good about that and I can wear a smile through all that. When it comes down to how I'm feeling inside, like in my heart and my soul, I'm really lonely. I'm so depressed about that. And if I think about that I just want to cry and it's . . . I miss my life. I do.

I want my life back. And it just feels like I don't have any more. I feel like I'm leaving something else and I'm having to start somewhere else and it's just . . . I don't feel like a teenager. I don't feel like I'm doing things that I used to do. I used to go out and have fun and I used to laugh and laugh and I used to have all my friends. I basically had no worries. I was going to school, I was doing good in school, I was having a blast. I had wonderful friends, I had high hopes, especially for this year my junior year. I mean I really had some hopes. I was gonna get a job, I was going to get really serious and buckle down in school. I was gonna start planning out for college, get my card, be driving. I was gonna have a very good life this year. And it's like all this stuff has been put on hold. I can't go get a job because I never know when I'd be calling in sick or can't . . . that's just something that's not predictable and I can't really . . . I haven't really had the concentration to start studying for driving and I just haven't . . . I can't do any of this stuff and it's just . . . it's really mad me very, very mad. But I'm not being able to do that. And then I'm just really sad because I'm
thinking about it. And it's like no one can understand this and it's like I feel so alone and so sad.

And I don't have . . . it's like I don't even have good dreams anymore. It's just everything is just sad. And I can't even . . . I try to look forward to my sister having this baby and I can't even get excited about it. I would usually be really excited about all this stuff but I can't even make her feel good about it. Like make her feel like I'm happy but I try to but I just can't get happy about anything anymore. It's like I am such a . . . I feel like the driest person and just so. just cold because I just don't . . . I don't feel like me anymore and I don't feel like I really have a life. And Jessica, my sister, she's like, you know, just looking at you makes . . . she was just kidding around with me yesterday, she says, but just looking at you makes me so depressed. You're never smiling anymore. And I'm just like, well, thank you for reminding me. I just really can't explain it. I'm just really depressed and a little bit angry. And I never was angry but I'm a little bit angry now. I'm very aggravated . . . and it's just like this has taken my life away. It's just like this has taken everything from me. It's taken from me physically and emotionally. It's taken my health, it's taken my hair, it's taken my . . . it's taken all my happiness away, it's just taken everything. All the things that used to make me the way I was . . . it's gone. And sometimes I just feel like empty, like you could just drop a ball down and just it would bounce . . . I just feel empty.

I asked her what has brought about this depression or change in how she looked at the world and herself. She replied:

. . . The constant symptoms and the not being able to help it. The treatment's done it all. I don't like it. I don't. It's . . . because I didn't have all this stuff before the
treatment. I never, never felt like this. I’ve gone through a lot of stuff this year. I moved, I’ve lost friends. All this stuff going on. That never really broke me but it’s like, this is the one that just broke the camel’s back. Now I’m just like, I’ve had too much. I don’t even feel like me any more.

Unpredictability of symptoms.

As in the first interview, Abby wanted to make it known she did not have any clear knowledge, mainly because she was not properly informed of how severe her symptomatic response would be and how she might react to this symptomatic response. She described the relentless nature of her symptoms:

If someone would have really told me, I probably would have been like, oh well, it’s gonna be hard but it wouldn’t really strike me. It wouldn’t sink in because I really haven’t felt it yet. And then when I started to feel it, it was just this thing that, it never goes away. It’s just this constant reminder that this is how it’s gonna be for a few more months. This is how it’s gonna be just . . . and there’s no one that really . . . everybody wants to . . . my parents ask me sometimes when I feel really bad and I’m feeling down, what’s wrong. And I just feel like I’m suffering something really bad, I just feel like, just total crud, I just feel terrible. And sometimes they’re like . . . my dad comes downstairs and I’m rocking and he says, “what are you rocking for, what’s wrong now?” And I’m like . . . I just cannot tell you. I don’t understand. And he’s like, well then stop rocking. And I’m like, I can’t. And they want to know why I do it and I can’t explain. It’s just something I do. And it’s the one thing that actually kind of soothes me. If my stomachs aching and if I rock, I don’t feel it so bad.. If I sit still.
it feels like it’s all getting worse and worse and I’ve gotta do something to keep my mind off of it.

Once again Abby talked about her confusion about the treatment that is supposed to cure her and make her well has made her so sick. She couldn’t stop thinking that prior to treatment, when she just had cancer, she felt fine. It struck me that perhaps her focus on the illogical nature of the cure being worse than the treatment meant she did not really trust that something that felt this bad would actually help her.

Along the same lines, she felt it was important for me to know that the individual symptoms occurring were not what made it difficult but rather the constellation of symptoms that came together. She described a domino-like effect, in which one symptom would bring on another symptom, and then that one would bring on a different symptom, until it became difficult to tell which was the originating symptom that had started this cascade.

Abby seemed to feel that the terrible symptoms would be bearable if she had some idea of how long she would feel bad and when she would start to feel better. Even at this point in her treatment, about to endure her fourth cycle, she was unable to isolate any patterns to the intensity and duration of her symptoms that would allow her to persevere. She described her frustration of not being able to anticipate, predict, or control her experience with the symptoms:

If you knew, if they said this day you’re gonna feel terrible, this day . . . but then this day you’re gonna feel better. Then on the days that I feel good, I’d really live it up. I’d do everything I wanted to do all that week and then the next day I’d just probably not get out of bed if I knew I was going to be sick.
Cascade of symptoms.

As stated previously, according to Abby, the symptom experience was made more difficult not by the individual symptoms occurring in isolation but rather how all of the symptoms occurred together. For Abby, the appearance of one symptom usually meant another symptom would appear. Symptoms triggered other symptoms, making the experience difficult.

Sometimes I just get so angry because I’m so aggravated and everything triggers each other. It’s just that this sets this off and this sets that off and . . . I have no control over it. None so ever. It’s just gonna happen. And I just have to deal with it. And I hate that I can’t do anything about it. It’s just they’re saying, well sorry, you have to do it anyway. And I’m just like, huh, I can put up a fight against it but it’s not gonna do me any good.

Comparing cycles.

One of the questions I asked Abby to see if she could separate out some of the singular symptoms from the whole constellation was, “If you were a scientist working on making chemotherapy symptom free, what symptom would you work on first.” This question was centered around ascertaining what was the worst symptom for Abby. She replied:

I don’t know because each chemo I’ve had something really bad with it and I think it’s always been . . . I think the worst one was the first one. I know that that was the worst. Because that was with the allergic reactions and that was horrible pain and I never want that again. But the one thing that I’ve had with me through each and every one that’s been really bad is the constant nausea and the just feeling sick to my stomach and the thought of chemo itself making my stomach turn like unbelievably
nothing else has made me sick to my stomach in this whole world. I mean I would rather watch this gory film and all this really nasty blood and just gore then think about going back to clinic. It’s the thinking about chemo that’s makes you feel so sick.

Each cycle of chemotherapy brought about a focus on a different symptom. She seemed to feel that her response to each of the three cycles she had endured thus far were widely different with respect to the most troublesome symptom. And even though she took a stand for nausea being the worst symptom, she could not help feeling that other symptoms deserved a close second:

For me the other thing that I’ve experienced that was really bad is the . . . I know everybody gets the bone pain . . . I’d get rid of the bone pain but I haven’t really had it bad lately. So I guess the constant fatigue and loss of strength because sometimes I get there and I can’t even really hold my glass up to my mouth. My hands get really weak, my arms get weak, my legs, my whole body. Sometimes all I can do is lay down. If I sit up I’m dizzy or something. And it’s just that constant fatigue. And then when I’m all tired, I’m so emotional. I was watching a commercial the other day and it was about chemotherapy and fatigue and it was this old guy and he was saying, are you going through chemotherapy? And I was saying, yeah, yeah. And he said are you constantly tired? Yeah, yeah, I’m so tired. And he says, does it keep you from doing the things that you usually like to do? At that point, I’m crying and I’m saying, I know what you’re saying. And then I’m just . . . I get tired of being tired and tired of being sick and it’s just . . .
Several times during this interview Abby brought up her thoughts of wanting to quit treatment. Even though she knew it would not be the right thing to do and she knew her parents would never allow her to quit, she explored this notion with me in the interview. At the same time as presenting why she would want to quit her treatment, she presented why she felt that she would not quit:

I'm tired of it. First time I went through it, I was like, this is OK. I can do this and still have energy for the next one. It was like that up until about the third chemo and I started getting tired of it. But this time I'm just really tired of it. I'm tired of waking up in the morning and not being able to come downstairs. I wasn't a breakfast person but now I know I have to eat something to keep my energy level up. And I come downstairs, my parents are like, you gotta eat this. Oh, the thought of food just makes me sick and then I get sick to my stomach and I'm throwing up in the morning. I'm tired of that being a part of my routine, waking up and not feeling good. And then I'm tired of going to sleep and not being able to get comfortable and I'm tired of always saying, oh, I don't feel good. I'm tired of hearing myself say it. But then I can't not say it because when I don't feel good, it just kinda comes out. My mouth just kinda goes, I don't feel good. And then I'm just tired of the whole thing. I'm tired of going to the hospital. I am so tired of the routine, accessing the port and . . . I'm tired of the clinics.

. . . And the good side is looking forward to the future side. And the other side is, I'm really going through this and this is horrible and I hate it kind of side. I've got something that looks forward to the future and the other part is just kind of living in the now. It's just saying you know, this hurts, that hurts, this is not going to go
away today, you’re not gonna be able to sleep tonight. And then you worry about sleeping and then when you can’t sleep, it drives you crazy and you wake up in the morning and you just want to sleep and you can’t sleep.

Abby talked about the difficulty she had been having in concentrating long enough to get any of her home-school work assigned by the tutors. She was frustrated with herself and embarrassed because she was previously a very good student who enjoyed learning.

Interview #4 — Treatment Day 85

This interview took place on Abby’s last day in the study and was also 14 days following her sixth cycle of chemotherapy and 1 day prior to her seventh cycle. The two main concepts Abby used to organize her talk about her symptom experience in this interview were (a) anticipatory anxiety and (b) comparing cycles.

Anticipatory anxiety.

In this interview, I asked Abby to describe her most prevalent fear at this point in her treatment. She replied:

I fear that every single one is going to be a long-term . . . like between each one it’s gonna be a full term of just being sick. I fear that. I fear . . . like I don’t know how long I’ll be sick every time. And I’m . . . I have really good faith that this won’t happen but I’m just . . . there’s a little bit of worry that like what if they say I need more treatment than I’m gonna have already. That will make me so mad. I will never get over that anger. I will be so angry, so . . . but I have a little thought in there that . . . I don’t think it will. But knowing that it could, it just bothers me that it could. I want to say that it can’t possibly happen. But I can’t say that, so . . . but I think that’s
the biggest. Just not knowing how bad it’s gonna be between chemos and how long it’s gonna last one.

In this interview, Abby continued to talk about the illogical nature of the treatment being worse than the disease. She described her frustration with this fact:

Cancer didn’t make a difference. It didn’t mean anything to me. I mean, the symptoms that I had from the cancer itself were just minor. I mean, I was still living. I was going out and doing stuff, it didn’t matter. And I was still happy. So but when I started getting the cure, it was really bad. It’s like the cancer’s fault that I had to get the cure. But I think . . . the cure . . . physically it feels a lot worse than the cancer. And nothing went downhill when I just had cancer. I didn’t even know I had cancer. For a long time I just did not even know.

**Comparing cycles.**

Contrary to the manner in which she talked about the progress of her symptoms from cycle to cycle in the previous interview, Abby felt that the cycles seemed to be getting easier for her. She felt that the symptoms did not last quite as long. Yet, as shown in the following quote, she was not totally sure she believed this:

Each chemo had a different effect on me, and it seemed like it got from the worst. I guess it was the worst because it was my first and it was really new for me. I don’t really know, but it was really bad. And then I started to get . . . It was all bad, but it got a little bit easier as it went along, and it didn’t last quite as long or something. It was all different. And, I think the last one, not this one that I’m going through right now, but the last one, my #5 was probably the best one. Even though I had anxiety, but not feeling so sick to my stomach everyday and everything, it was a lot easier.
That was the easiest one. But, I don’t know why it was so easy, ’cause we did the same thing this time and I still had a hard time with it. But, this one was just the bad heartburn and the constant, just, sick to my stomach all day long, all night long, all morning. I think Friday was my starting to get better day. And it started off bad, but then it got better later on in the day, but I think that would be about a little over a week. But if I’m not nauseous, I have something else. After, like, a big thing was. I have like little bitty spurts of energy throughout a day. Like I’ll be able to do a lot of stuff at once, but then for a lot of the day I’m just kind of really mopey and really tired and just really weak and just wanting to lay around and just be a bum basically.

Summary and Conclusions: Within-Case Generalizations

Abby’s verbal descriptions of her experiences with the treatment symptoms were very rich and full of information. The organizing framework from which she seemed to view all of her symptoms was through larger, abstract concepts that represented how she responded to her symptoms. Abby’s response to her symptoms frightened her, and she felt that maybe she was not up to the challenge: “If I can’t fight the treatment, how will I fight the cancer?”

In general, Abby’s case could be characterized as that of worry that changed into anxiety over the course of the study. Her anxiety took on behavioral manifestations in response to the uncontrolled symptoms. Abby was very distressed by the unpredictable nature of her symptoms and thus her experience could be described as one of vulnerability. Pain, fatigue, and nausea were the three most prevalent and bothersome individual symptoms that Abby discussed in her interviews. However, her experience with symptoms was more strongly related to how the symptoms occurred in concert rather than how they occurred individually.
Michael

I first met Michael on September 30, 1998, in a private hospital room on the fifth floor of a university teaching hospital. He was sitting quietly in a hospital bed and was watching a television program. His father was asleep in a lounge chair beside the bed. Michael was a 12-year-old African-American boy. Two days before I met him, he had been transferred to this room from a hospital in his community some 70 miles away, where he had spent 5 days recovering from the surgical removal of his left kidney. Michael’s health problems up to this point had included little more than reactive airway disease. In his accounting of how he came to be in this place at this time he stated:

I had fell one day when I was at the bowling alley and one morning, Friday morning, I woke up and I was passing blood through my urine. So I went to school that afternoon and when I came back that afternoon my side was hurting and I went to the hospital. . . . Then they put me in the hospital for having a tumor on my left kidney. and it was swollen.

From Michael, his mother, and notes made in his medical chart. I was able to put together the following account of events that occurred prior to the initiation of Michael’s treatment. Beth, Michael’s mother, brought him to the emergency department of his community hospital the day following his report of blood in his urine and pain in his side. A computerized axial tomography scan revealed a renal mass that was interpreted as a contusion. He was sent home and instructed to rest. When the hematuria continued over the next day, Beth and Michael returned to the emergency department, whereupon the contusion was diagnosed as a renal mass. Beth was instructed to consult a surgeon regarding this mass. Three weeks passed between the instructions for a consultation and the removal of the
kidney. Beth reported to me that she had great difficulty getting an appointment with the surgeon to whom she was referred. The surgeon reported in his notes that Beth did not keep the appointments given to her.

Michael underwent a left nephrectomy on September 24, 1998, at his community hospital and was in his second day of recovery, when the staff nurses caring for him telephoned the Chief of Pediatric Oncology at a university medical referral center and reported his situation. They requested he be seen by experts in the field, as they seemed to feel that his medical needs were not being met. Medical chart notes indicated that, although there was some anger over this transgression on behalf of the treating physician, hospital advocacy personnel at the university medical center interceded on behalf of the nurses and stated that they had acted in an ethically correct manner and had advocated for their client.

Michael was immediately transferred to the pediatric oncology unit in the university medical center to recover from his surgery and begin a complete work-up so that treatment decisions could be made. On September 28, 1998, he was given a preliminary diagnosis of left renal carcinoma and was awaiting further analysis of the tumor that was removed with his kidney. Beth reported upon Michael’s admission that he had a 1-month history of significant weight loss (22 lb) along with feelings of fullness in the left side of his body. At this point in time, I met Michael and his parents and they agreed to participate in the study.

Table 6 depicts the chronology of events that unfolded prior to Michael’s induction into treatment. He was enrolled into my study on September 30, 1998, and was discharged home on October 2, 1998, to await tumor cell identification. On October 6, 1998, Michael returned to the hospital for a procedure to insert his Infusaport, a central venous line
surgically placed into the left subclavian vein. He began his first cycle of chemotherapy on October 7, 1998.

Table 6

Michael's Chronology of Diagnostic Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>August 28, 1998</td>
<td>community ER with gross hematuria</td>
</tr>
<tr>
<td>September 24, 1998</td>
<td>community hospital OR for left nephrectomy</td>
</tr>
<tr>
<td></td>
<td>dx: renal tumor</td>
</tr>
<tr>
<td>September 28, 1998</td>
<td>transfer to University Medical Center</td>
</tr>
<tr>
<td>September 30, 1998</td>
<td>enrolled into study</td>
</tr>
<tr>
<td>October 6, 1998</td>
<td>OR: central line placement</td>
</tr>
<tr>
<td>October 7, 1998</td>
<td>dx: renal medullary carcinoma</td>
</tr>
<tr>
<td>October 8, 1998</td>
<td>chemotherapy Cycle #1 begins</td>
</tr>
</tbody>
</table>

On October 6, the biopsy taken from his renal mass showed Renal Medullary Carcinoma with vascular invasion and positive metastases to the lymph nodes in the area surrounding the kidney. Renal medullary carcinoma is a rare cancer found mainly in black adolescent males. In all cases, this disease has been fatal within a median of 52 weeks following diagnosis (Davis, Mostofi, & Sesterhenn, 1995). In addition, a scan of the chest and bones revealed probable metastases to the lobes of the lungs and bones of the pelvis and hips. Michael’s parents and the oncology team decided to proceed with treatment despite this
diagnosis. Medical chart notes written by the physician revealed that Michael’s parents had been fully informed about the gravity of the prognosis given to their son, and that the medical center felt that treatment with chemotherapy did offer him a small chance of survival.

**Treatment Protocol**

Michael was enrolled into my study on September 30, 1998, and recorded data regarding his symptomatology twice daily for 77 days, through December 16, 1998. Michael died on March 15, 1999, peacefully at his home.

During the period of time he was in my study, he had five hospital admissions to the inpatient pediatric oncology unit at the university medical center. Three of the admissions were for chemotherapy administration and two were for problems with fever and infection. Of the 77 days in the study, he spent 40 days (52% of total study days) hospitalized and 37 days (48% of total study days) at home. His first cycle of chemotherapy began on October 8, 1998, and was given over 4 days. He had three such cycles, with the last one given on November 19, 1998. Michael spent 4 days in the pediatric intensive care unit, and it took him 5 days to recover from the infection that made him so critically ill. No data were collected during this 9-day period.

The agents used in Michael’s chemotherapeutic treatment protocol (see Table 7) can be classified based upon their emetogenic potential as three agents with a high emetogenic potential, one agent with a moderate emetogenic potential, one agent with a low emetogenic potential, and one agent with a very low emetogenic potential (Chase & Staggs, 1990).
On the days in which Michael was hospitalized, I conducted data collection visits with him twice daily. Each visit lasted approximately 15 min. During these visits, I collected his saliva for cortisol assay and picked up his diary sheets for that day. On the evening visit, I applied the Actiwatch to his wrist and removed it on the morning visit.

On the days in which Michael was at home, I conducted data collection visits twice a week at his home, during which time I picked up his completed diary sheets and cortisol samples and replaced the data collection supplies. These visits generally lasted approximately 30 min. Michael’s home was approximately 60 miles from the university medical center. Michael, his mother, and his 10-year-old brother lived in a small one-bedroom apartment in a small rural town. Michael’s mother was employed part-time at a fast food restaurant. She did not have any personal transportation and relied upon extended family for travel to the hospital. His father was unemployed and was incarcerated throughout a portion of the study period. As a result of Michael’s somewhat unstable home environment, I decided not to collect the sleep data while he was at home. I did not want to burden Michael’s mother with

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Protocol Phase</th>
<th>Date</th>
<th>Chemotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Regular Therapy</td>
<td>10/08/98 – 10/11/99</td>
<td>Cyclophosphamide, Doxorubicin, Vincristine</td>
</tr>
<tr>
<td>2</td>
<td>Regular Therapy</td>
<td>10/29/98 – 10/31/99</td>
<td>Cyclophosphamide, Doxorubicin, Vincristine</td>
</tr>
</tbody>
</table>

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the responsibility for an expensive piece of laboratory equipment. Sleep data hence was collected only while he was hospitalized.

On three separate occasions throughout the data collection period, I conducted a tape recorded interview with Michael in his home. I had wanted to interview him in the hospital, but he requested that we conduct them only in his home. Each of these interview sessions lasted approximately 20 min. Michael's verbal responses to my taped interview questions were very limited. He became very anxious and subdued when the tape recorder was turned on. This reaction occurred consistently throughout all taped interview periods and thus the data from these episodes were limited. However, Michael enjoyed recording data in the Symptom Diary, and I was able to get a moderate amount of data regarding his symptom experience in the form of field notes taken from conversations I had with Michael while taking part in a leisure activity with him.

**Self-Report Data and Biobehavioral Data**

Data were collected using the following self-report and biobehavioral methods: a daily symptom diary; the Oucher pain scale; the Pediatric Nausea, Vomiting and Retching scale; the Revised Children's Manifest Anxiety Scale; salivary cortisol assay; and Sleep Actiwatch. Michael very consistently completed his symptom diary.

**Symptoms**

**Pain.**

As shown in Table 8, Michael's scores on the Likert pain scale ranged from 1 to 2, with a mean of 1.02 ($SD = .14$). These summary numbers in addition to Figure 22 indicate that Michael reported no pain over the course of the study. Michael's Oucher scores ranged from 0 to 40, with a mean 1.20 ($SD = 6.08$). His morning Oucher scores were slightly higher.
than were his evening scores, as shown in Figure 23, but the differences were slight. Figures
24 and 25 show his morning and evening pain and Oucher scores plotted by day since
treatment administration. His morning scores on Day 18 were much higher than on any other
day.

Table 8

*Michael's Mean Symptom Scores*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Scores</th>
<th>All</th>
<th>Morning</th>
<th>Evening</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>Range</td>
<td>M</td>
</tr>
<tr>
<td>Pain</td>
<td>1.02</td>
<td>0.14</td>
<td>1 - 2</td>
<td>1.02</td>
</tr>
<tr>
<td>Oucher</td>
<td>1.20</td>
<td>6.08</td>
<td>0 - 40</td>
<td>1.87</td>
</tr>
<tr>
<td>Fatigue</td>
<td>1.33</td>
<td>0.58</td>
<td>1 - 3</td>
<td>12.96</td>
</tr>
<tr>
<td>Worry</td>
<td>1.03</td>
<td>0.17</td>
<td>1 - 2</td>
<td>1.04</td>
</tr>
<tr>
<td>Nausea frequency</td>
<td>1.25</td>
<td>0.58</td>
<td>1 - 3</td>
<td>1.23</td>
</tr>
<tr>
<td>Nausea bother</td>
<td>1.29</td>
<td>0.74</td>
<td>1 - 5</td>
<td>1.30</td>
</tr>
<tr>
<td>Vomiting frequency</td>
<td>1.31</td>
<td>0.81</td>
<td>1 - 5</td>
<td>1.44</td>
</tr>
<tr>
<td>Vomiting bother</td>
<td>1.20</td>
<td>0.51</td>
<td>1 - 3</td>
<td>1.22</td>
</tr>
<tr>
<td>Retching frequency</td>
<td>1.02</td>
<td>0.20</td>
<td>1 - 3</td>
<td>1.04</td>
</tr>
<tr>
<td>Retching bother</td>
<td>1.02</td>
<td>0.20</td>
<td>1 - 3</td>
<td>1.04</td>
</tr>
<tr>
<td>Cortisol</td>
<td>2.83</td>
<td>2.34</td>
<td>1.45 - 16.41</td>
<td>12.96</td>
</tr>
</tbody>
</table>
Figure 22. Michael's AM and PM pain over time.
Figure 23. Michael's AM and PM Ouchers over time.
Figure 24. Michael's AM and PM pain by day since treatment administration.
Figure 25. Michael’s AM and PM Oucher by day since treatment administration.
Fatigue.

Michael’s fatigue scores ranged from 1 to 3, with a mean of 1.33 ($SD = .58$). His morning fatigue scores were slightly higher than were his evening fatigue scores. as shown in Table 8. Figure 26 shows Michael’s morning and evening scores over time in the study. Although his morning fatigue scores showed higher peaks in the early portion of the study, both patterns were similar in that the peaks in the first 40 days in the study were interspersed with relatively long periods of no fatigue. In the last 10 days of the study, while still experiencing peaks in the morning, he experienced no fatigue in the evening hours.

Figure 27 shows Michael’s fatigue scores plotted by day since treatment administration. The blanks over morning Days 6 through 9 and over evening Days 6, 9, and 19 reflect periods in which he had no recorded data regarding fatigue. Approximately 25% of Michael’s data points on all variables are missing as a result of events occurring during the study, such as his admission to the pediatric intensive care unit and home events in which he was required to spend the night with relatives and did not have his diary with him. Michael’s morning fatigue scores over days since treatment administration showed a relatively stable pattern of low fatigue scores, with a peak at 18 and 19 days following treatment administration. His evening fatigue scores showed a peak at 7, 10, and 15 days following treatment administration.

Worry.

Michael’s worry scores showed he reportedly experienced little or no worry. His scores ranged from 1 to 2, with a mean of 1.03 ($SD = .17$). There was no difference between his morning worry scores and his evening worry scores.
Figure 26. Michael's AM and PM fatigue over time.
Figure 27. Michael's AM and PM fatigue by day since treatment administration.
Figure 28 shows Michael’s morning and evening worry over time in the study. His morning scores showed two very low peaks within the first months of the study followed by his reports of no worry throughout the remainder of the study. His evening worry scores showed only one very low peak in the second month of the study, preceded and followed by reports of no worry.

**Nausea.**

Michael’s frequency of nausea scores ranged from 1 to 3, with a mean of 1.25 ($SD = .58$). There was no difference between his mean morning nausea frequency score and his mean evening nausea frequency score, as shown in Table 8. Figure 29 shows Michael’s morning and evening nausea frequency scores over time. Both plots showed the same pattern of nausea response, but his evening nausea scores appeared to have higher peaks than did his morning scores. The peaks in both plots corresponded with the period of time during which Michael received his three cycles of chemotherapy, Days 1 through 4, Days 22 through 25, and Days 43 through 47. The peak nausea periods were followed by periods of consecutive days without nausea.

Figure 30 shows Michael’s morning and evening bother by nausea. The peaks on these plots corresponded with the peaks on the nausea frequency plots. Michael had moderate levels of nausea and moderate to high levels of bother by nausea while getting his cycles of chemotherapy. Michael did not experience nausea and was not bothered by it in the periods when he was not getting his cycles of chemotherapy.
Figure 28. Michael’s AM and PM worry over time.
Figure 29. Michael's AM and PM frequency of nausea over time.
Figure 30. Michael's AM and PM bother by nausea over time.
**Vomiting.**

Michael's vomiting frequency ranged from 1 to 5, with a mean of 1.31 ($SD = .81$). As shown in Table 8, his morning vomiting frequency was slightly higher than his evening vomiting frequency. Figure 31 shows his vomiting frequency over time. His vomiting pattern was characterized by intense periods of vomiting that were always followed by stable periods of no vomiting. Again, the intense periods corresponded with the three cycles of chemotherapy administration at Days 1 through 4, Days 22 through 25, and Days 43 through 47. The very high levels of vomiting suggest that Michael's nausea was not well controlled pharmacologically in spite of antiemetic therapy.

Michael's bother by vomiting frequency, as seen in Figure 32, showed the three major peaks that were seen in the vomiting frequency plots. There was no difference between his morning bother and evening bother scores. When I compared his bother by vomiting to his bother by nausea, I found that Michael's scores for nausea were higher than that for vomiting.

**Retching.**

Michael's scores on the retching scale ranged from 1 through 3, with a mean retching score of 1.02 ($SD = .20$). As shown in Table 8, there was no real difference between his morning retching scores and his evening retching scores. Figure 33 shows Michael's morning and evening retching frequency scores. Other than one small morning peak at the beginning of the study, Michael did not experience retching and, as shown in Figure 34, was not bothered by retching.
Figure 31. Michael’s AM and PM frequency of vomiting over time.
Figure 32. Michael's AM and PM bother by vomiting over time.
Figure 33. Michael's AM and PM frequency of retching over time.
Figure 34. Michael's AM and PM bother by retching over time.
Sleep.

Michael's sleep efficiency scores represent only those study nights during which he was hospitalized. His scores ranged from 55.0% through 90.7% efficient, with a mean of 77.66%. These scores indicate that in reference to the total amount of time he spent in bed trying to sleep, approximately one quarter of the time was spent not sleeping. Michael seemed to have been a fairly efficient sleeper, even though his sleeping environment was a private room on a busy pediatric unit with infusions of chemotherapy constantly running.

Figure 35 shows Michael's hospital sleep efficiency scores over the course of the study. His efficiency was moderately variable and tended towards lower scores near the end of the study, when Michael became progressively more ill.

Salivary cortisol.

Figure 36 shows Michael's morning and evening salivary cortisol values across the 77 days in which he participated in the study. Both curves showed a high peak between Days 35 and 40. As seen in Table 8, his evening cortisol levels were, on average, slightly higher than were his morning cortisol levels. Figure 37 also shows that the majority of his evening cortisol levels were higher than were his morning cortisol levels. Thus, there is no normal diurnal pattern of high morning levels turning into low evening levels, suggesting that Michael's HPA axis response was being stimulated by something other than the circadian clock. He experienced periods of stress throughout the day, which stimulated the HPA axis excretion of cortisol throughout the day.
Figure 35. Michael's hospital sleep efficiency over time.
Figure 36. Michael's AM and PM salivary cortisol levels over time.
Figure 37. Difference between Michael's AM and PM salivary cortisol levels over time.
Figure 38 shows Michael’s morning and evening salivary cortisol levels plotted by day since chemotherapy administration. In the morning, his cortisol remained at fairly constant levels, except for post-chemotherapy Day 11 and Day 14. In the evenings, his cortisol levels were also fairly stable with the exception of post-chemotherapy Days 13 and 23. Thus, Michael’s excretion of cortisol does not seem to have been affected much by his chemotherapy cycle and the symptom experience that accompanies this cycle.

**Anxiety.**

Michael completed the Revised Children’s Manifest Anxiety scale once each month while in the study. Table 9 shows how his total anxiety score increased steadily from the first testing, done at study enrollment, through the second testing done at Day 36, to the final testing done on his last day in the study. These are standard scores based on matched age and race normative samples. For the total scale score, the population norm has a mean of 50 and standard deviation of 10. Thus, Michael’s first two test scores fall approximately one standard deviation below the normative population of African-American, 12-year-old boys.

The three subscales, physiological anxiety, worry/oversensitivity, and social concerns/concentration, have a normative mean of 10 and standard deviation of 3. Thus, any standard score greater than 13 indicates a child that may be having difficulty on a particular subscale. On the physiological anxiety subscale, Michael’s scores steadily increased from below the normative mean, to within one standard deviation of the normative mean, and finally to above one standard deviation above the normative mean. Thus, Michael experienced some physiological anxiety that developed over the course of the study.
Table 9

*Scores on the Revised Children's Manifest Anxiety Scale Over Time*

<table>
<thead>
<tr>
<th>Scale &amp; Subscales</th>
<th>Day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>01</td>
</tr>
<tr>
<td>Total anxiety</td>
<td>38</td>
</tr>
<tr>
<td>Physiological anxiety</td>
<td>7</td>
</tr>
<tr>
<td>Worry/Oversensitivity</td>
<td>7</td>
</tr>
<tr>
<td>Social concerns/concentration</td>
<td>13**</td>
</tr>
</tbody>
</table>

** scores falling more than one standard deviation above the norms
Figure 38. Michael's AM and PM salivary cortisol levels by day since treatment administration.
His scores on the worry/oversensitivity subscale remained fairly constant and below the normative mean. His scores on the social concerns/concentration subscale varied over the course of the study. He started out one standard deviation above the normative mean, dropped below the mean, and finally ended up at the normative mean. The instability in his scores on this subscale reflect his changing feelings regarding his social or interpersonal skills and his frustration with concentration and attention.

Summary of Self-Report and Biobehavioral Data

The trends in Michael's self-report of symptoms are that of low variability with few intense peaks. Michael rated all of his symptoms, pain, nausea, vomiting, and fatigue on the no or very low end of intensity. The only trend that can be seen is that, when he rated his symptoms as higher than no symptom intensity, it was most often in the morning hours. Very often, Michael's ratings did not concur with other data that were available regarding his symptom occurrence, such as his mother's report or the notes in his medical chart. It seemed as though he was operating under the pressure of social desirability when filling out his diary in that he did not like to reveal when he was not feeling well.

Michael’s Interview and Field Note Data

I interviewed Michael formally, with a tape recorder on, while he was sitting at his kitchen table at home or while he was sitting up in bed at the hospital, at three different times over the course of the study. The first interview took place on October 13, 1998, or Study Day 6, the second, on November 1, 1998, or Study Day 32, and the last, on December 16, 1998, or Study Day 77. Michael did not seem to enjoy these formal interview situations. Once the tape recorder was turned on, he withdrew from me and in general answered using only yes and no questions. However, Michael did provide me with data on his experiences.
with treatment on various occasions at home and in the hospital, while I was collecting the quantitative data. I kept field notes on these visits, recording anything that he said in reference to his symptomatology. Thus, this analysis includes data taken from the tape-recorded interviews as well as from my field notes taken during data collection visits.

As a result of Michael's reluctance to be interviewed, I have organized this analysis based upon time points in his treatment, at which time the data were collected as opposed to actual interview dates.

I have come to view Michael's symptom experience as a case of obligation or duty. As demonstrated through the analysis of his qualitative data, Michael seemed to feel that the unpleasant symptoms he experienced as a result of chemotherapy were part of his duty, or obligation, to the illness with which he was afflicted. Michael felt that all children had to do to get through their treatment was "just get use to it."

**Study Days 1–22**

I began collecting qualitative data on Michael's symptom experience on my first home visit with him following a 6-day hospital stay during which he received his first cycle of chemotherapy. Michael had difficulty telling me specific details about his treatment and the effects it was having on him. He talked about his hospitalization in terms of being away from home and school instead of the symptoms from which he suffered. He did not know a lot about his treatment and the purpose of his treatment, saying that "Most of the time I was out in the room when they told about that stuff. They said that they didn’t have the right medicine there that they were going to transfer me to [university medical center]."

Michael said that he did not worry a lot about his treatment or having to stay at the medical center. The only worry I ever heard Michael verbalize over the period of time in my
study was said during this initial treatment period after he had one cycle of chemotherapy. He said, “I am worried about the treatment and will it help my situation?”

Michael liked to describe himself as not scared or not worried. As the oldest child in a home with a single mother, Michael seemed to want to protect his mother from worrying too much about him. He described his mother’s reaction to his first cycle of chemotherapy, saying “she seemed nervous. I think she was shaky.” He was worried about his mother and how she was going to get through this “whole situation.”

At several points during this first data period, I asked Michael about the kinds of things he would like to tell another 12-year-old boy who was about to get his first cycle of chemotherapy. His replies at various points were:

“Well I wasn’t really scared. Not me, not really.”

“It makes you feel sick some.”

“The chemo? Ya, you’ll be sleepy a lot.”

“And you mostly feel some pain. I don’t really know.”

“I was sore. Just where I had the surgery.”

“Drowsy. Dizzy. Wouldn’t much I could do.”

“Wouldn’t much to be worried about.”

Nausea and vomiting.

Contrary to Michael’s self-report data on which he reported very low levels of nausea and vomiting, my observations and his chart reports indicated that Michael did experience moderate levels of both nausea and vomiting. However, in concordance with the self-report data, these symptoms did not seem to lead to much bother. He talked about how the
chemotherapy made him "feel sick to my stomach like I had to vomit." But he said that he was able to find relief from the nausea by eating something and drinking apple juice.

**Hospitalization.**

Michael talked to me about the effect being in the hospital had on him. He was surprised about the number of people who came in and out of his room every day. He was also surprised by the large number of relatives who visited frequently.

**Study Days 22–40**

After 17 days at home, Michael had been readmitted to the hospital for his second cycle of chemotherapy, which he received on Study Days 22 through 25. During this period of time, Michael and I continued to talk about his knowledge of treatment. He told me that he wished someone could have explained to him what it would feel like to get chemotherapy because it was a big surprise to him. He would really have liked to have been given more information about his Port-a-Cath (central venous line device).

Michael tried to outline for me at what time following chemotherapy administration he first began to feel symptoms. He thought that, in general, he did not really feel anything on the first or second day. But once the third day after chemotherapy came, things started to change. He felt that the major changes were that he felt very tired and did not feel like eating. This third-day effect was true for all of the symptoms except nausea, which arrived a day earlier than the remainder of the symptoms.

Michael described his pain and fatigue caused by treatment as being fairly constant. Once these symptoms arrived on the third day, they remained throughout the rest of the cycle even when he was at home. Michael felt that most other children receiving chemotherapy probably felt scared and cried a lot. He said the treatment did not affect him in this manner.
because he “tried to get use to it.” When I asked him if there was any one thing that he worried about while getting his treatment he replied that “there is a fear of going outside your body.” Michael would not elaborate on what he meant by this statement.

**Study Days 40–56**

Michael had a prolonged admission to the hospital throughout this data period. He did not go home for 17 days, and his status became so guarded during this period of time that he spent 3 days in the pediatric intensive care unit. During his stay in the intensive care unit, I suspended data collection. After 2 days, I went to the unit to visit him. Michael responded:

> Where have you been? I been stuck in here and you haven’t been around. When I asked him why he wanted to see me so badly he replied, “You suppose to be asking me how sick I feel. This is the worst sick I have felt yet. The people from the Make A Wish come by to see me. I think everyone thinks I am going to die.”

Thus, it appeared that Michael was very concerned and worried about how sick he felt. This was the first time he had actually verbalized a worry to me.

I asked Michael some questions about whether he thought he was going to die. He responded no. We then talked about which symptoms were bothering him the most while he was in the intensive care unit. He was experiencing severe pain in his head that was not being well controlled, and he said this pain was keeping him up at night. He also complained of pain when he took a breath. Pain seemed to be his most troublesome symptom during his stay in the intensive care unit. Michael also described to me how difficult it was for him to sleep while in the open unit. He said that babies were crying all night long. Once his status stabilized, Michael was transferred to the pediatric oncology unit to recover enough to withstand his next cycle of chemotherapy.
The main theme Michael talked about during this time was that he felt staying in the hospital made getting chemotherapy hard for him. I asked him what he hated the most about staying in the hospital and he said that it was just being away from home for so long. He said that chemotherapy would not be so bad if he could get it at home. Michael received his third cycle of chemotherapy on Study Days 43 through 47.

**Study Days 57 – 77**

Michael compared the previous three cycles of chemotherapy and felt that this last cycle was easier than the previous two had been. Although his nausea was bad with this last cycle, he felt that the nausea he experienced during his first and second cycles was much worse. I asked him why he thought it was not as bad this time, and he replied that he got used to it and knew what to do to make it better. He said that he did things like watch television or play Nintendo. He also liked to get some medicine and sleep throughout the nausea.

I asked Michael how well he thought the treatment was working for him. He said that he thought it was working just fine because the doctor told him that half of his cancer was gone and he thought that very soon it would all be gone and he could stop the treatment at that time.

**Summary and Conclusions: Within-Case Generalizations**

Michael preferred to describe his symptom experience as consisting of no symptoms and little or no bother. His scores over all diary variables were consistently low in intensity and variability. It was difficult to obtain qualitative data from Michael as he was not as responsive to questions as the first case presented had been. He required much more support, in terms of probing, and was less spontaneous with his answers. I learned to pay close attention to what Michael was saying to me at all times while in his presence, as most of his
talk about his symptoms and his emotional response to his symptoms occurred when I was not using a tape recorder.

Michael's qualitative data indicated he had troublesome experiences with pain and nausea. His self-report data do not support this conclusion. He seemed to have accepted these symptoms as part of his treatment or part of the "situation he had gotten himself into." This blind acceptance, duty, or obligation he seemed to feel appeared to help make his progression through the most intense periods less distressful. Because Michael seemed to feel as though he did not have a choice over feeling bad or feeling good, he appeared to just move along with his treatment cycles instead of fighting against them.

Pain, nausea, and fatigue were the main symptoms Michael discussed with me. He seemed not to feel as though he was having any problems with sleep, worry, vomiting, or retching. I was cautious in making generalizations with Michael, as I did not want to assume that because he did not talk about a symptom meant it did not bother him. Along the same lines, calling Michael's symptom experience one of acceptance could also be dangerous. While he did provide some verbal and behavioral data that supported the notion that this was the process by which Michael coped with his symptoms, it could also be that he internalized his worry, anger, and isolation so much that it was not accessible.

Rachel

I first met Rachel on January 14, 1999, in her private room on the fifth floor pediatric oncology unit of a university teaching hospital. This 7-year-old, Caucasian girl, with long blond hair was asleep in her bed. She had several lines pumping the first doses of her initial cycle of chemotherapy through a central venous access device in her chest wall. I sat and talked with Jeanne, Rachel's mother, for approximately 2 hr and listened as she recounted the
series of events that had led them to be in the hospital. After obtaining Jeanne’s consent to allow her daughter to participate in my study, I told her that I would return in a few hours to describe the study to Rachel and see if she was interested in taking part. When I returned, Rachel was sitting up in bed with a big smile on her face and said, “What kind of stickers will I get to use in the diary?” After a brief discussion, she eagerly gave her assent to participate.

Jeanne told me that Rachel, who previously had suffered from the usual childhood diseases, was sick with influenza prior to and throughout the Christmas holidays. Three weeks prior to her diagnosis, she began complaining of abdominal pain, had low grade fevers, and would vomit each evening. Jeanne had noticed that Rachel had looked tired and lacked energy over the 3 weeks preceding her diagnosis and that she had lost more than 3 lb in 1 week. Following the Christmas holidays, Jeanne and Adam took Rachel to her pediatrician who diagnosed her as having constipation. On January 11, 1999, when the abdominal pain, vomiting, and fevers persisted, she was brought to the pediatric clinic where the pediatricians noted irregularities in her blood tests. A bone marrow aspiration and biopsy was performed, and she was subsequently diagnosed with Acute Myelogenous Leukemia. Table 10 depicts the chronology of events that unfolded prior to Rachel’s induction into treatment. She was enrolled into my study on January 16, 1999.
Table 10

Rachel’s Chronology of Diagnostic Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>December 14, 1999</td>
<td>fatigue, decreased energy, vomiting each morning, to January 4, 1999</td>
</tr>
<tr>
<td></td>
<td>low grade fevers</td>
</tr>
<tr>
<td></td>
<td>complaints of abdominal pain</td>
</tr>
<tr>
<td>January 4, 1999</td>
<td>to pediatrician &amp; diagnosed with constipation</td>
</tr>
<tr>
<td>January 11, 1999</td>
<td>to pediatric clinic at University Medical Center</td>
</tr>
<tr>
<td></td>
<td>diagnosed with AML</td>
</tr>
<tr>
<td></td>
<td>admitted to pediatric oncology unit</td>
</tr>
<tr>
<td>January 14, 1999</td>
<td>to OR: central line placement</td>
</tr>
<tr>
<td></td>
<td>received first dose of Cycle I chemotherapy</td>
</tr>
<tr>
<td>January 16, 1999</td>
<td>began data collection</td>
</tr>
</tbody>
</table>

Treatment Protocol

Rachel was enrolled into my study on January 16, 1999. Data were collected from her twice daily, for 84 days, through April 9, 1999. Over the 84 study days, Rachel spent 57 days (68% of total study days) in the hospital and 27 days (32% of total study days) at home. Her hospital stays consisted of two admissions. Her first admission lasted from the time she was diagnosed on January 11, 1999, until March 8, 1999. She was discharged home on January 30, 1999, but was readmitted with an infection and high fevers before the day was finished. Thus, I did not count this as a discharge. Rachel remained at home from March 9, 1999, through March 14, 1999, and was readmitted on March 15, 1999, until March 19, 1999. Following this discharge, Rachel remained at home throughout the rest of the study.
While enrolled in my study, Rachel received three cycles of chemotherapy. The length and description of each cycle is displayed in Table 11. The agents used in Rachel's chemotherapeutic treatment protocol can be classified based upon their emetogenic potential as (a) two agents with a high emetogenic potential, (b) one agent with a moderate emetogenic potential, (c) one agent with a low emetogenic potential, and (d) one agent with a very low emetogenic potential (Chase & Staggs, 1990).

Table 11

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Protocol Phase</th>
<th>Date</th>
<th>Chemotherapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Induction 1</td>
<td>01/14/99 – 01/20/99</td>
<td>Cytarabine, Daunomycin, Thioguanine</td>
</tr>
<tr>
<td>2</td>
<td>Induction 2</td>
<td>02/15/99 – 02/19/99</td>
<td>Cytarabine</td>
</tr>
<tr>
<td>3</td>
<td>Consolidation 1</td>
<td>03/15/99 – 03/19/99</td>
<td>Cyclosporine, Cytarabine, Etoposide, Mitoxantrone</td>
</tr>
</tbody>
</table>

While Rachel was in the hospital, I conducted data collection visits with her twice daily. Each visit lasted approximately 15 min. During these visits, I collected her saliva for cortisol assay, picked up her diary sheets for that day, and, on the evening visit, I applied the Actiwatch to her wrist and removed it on the morning visit. Interviews were conducted both while Rachel was in the hospital and at home.

On the days in which Rachel was at home, I conducted data collection visits twice a week, during which time I picked up her completed diary sheets, cortisol samples, downloaded Actiwatch data, and replaced the data collection supplies. These supervision visits
generally lasted approximately 1 hr. Rachel’s home was approximately 60 miles from the university medical center. Rachel, along with her mother, father, and 2-year-old brother, lived in a large four-bedroom home in a small rural town. Rachel’s mother was employed part time as a civil engineer in the university hospital at which Rachel was being treated. Her father was a pilot for a large airline and thus was frequently away. Rachel also had extensive support from extended family who lived in the same neighborhood.

**Self-Report Data and Biobehavioral Data**

Data was collected using the following self-report methods: a daily symptom diary; the Oucher pain scale; the Pediatric Nausea, Vomiting and Retching Scale; and the Revised Children’s Manifest Anxiety Scale. The sources of biobehavioral data were the salivary cortisol samples and Actiwatch sleep data.

Rachel was admitted to the pediatric intensive care unit on Study Day 17 with a severe infection in her blood and pancreatitis. She spent 3 days in the intensive care unit and then was transferred back to the pediatric oncology unit with a nasogastric tube and was heavily sedated for the following 5 days. Thus, all data collection was suspended over that period of time. I continued to visit with Rachel, sit at her bedside throughout that period, and take field notes regarding what I observed of her symptomatology. The self-report data collection resumed at the end of this 8-day period. However, her nasogastric tube remained in for another week, resulting in dry mucous membranes. I was unable to collect saliva samples to measure her salivary cortisol throughout this period of time.

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Symptoms

Pain.

Rachel’s scores on the Likert pain scale ranged from 1 to 5, with a mean of 2.24 (SD = 1.33). As shown in Table 12, her morning pain scores were higher than were her evening pain scores. Figure 39 shows Rachel’s pain scores across the 84 days of the study. The pattern on these two plots show high peaks of severe pain in the first half of the study. Her morning pain peaks were followed by valleys of moderate intensity. Her morning pain levels did not fall below mild intensity in the first half of the study. In the second half of the study, Rachel experienced less intense morning pain. Her levels still had peaks, but they were fewer in number and of a lower intensity. In addition, they were followed by valleys of no pain. Her evening pain pattern is similar to the morning pattern with the exception that she seemed to have periods of relief from her pain. Her intense peaks in the first half of the study were followed by valleys of no pain.

Rachel’s mean Oucher score of 42.77 (SD = 42.56) indicates that she was experiencing a moderate amount of pain. As shown in Table 12, and similar to her Likert pain scores, her mean morning Oucher score (Figure 40) was higher than was her mean evening score.

Figure 41 shows Rachel’s morning Likert pain scores plotted by the day following her chemotherapy administration. On the day following her chemotherapy administration, Rachel experienced the highest levels of morning pain. On Days 10 and 24, Rachel also experienced higher levels of morning pain. The pattern for her evening scores was slightly different, in that Day 4 had the most intense evening pain scores. In addition, on the days in which she received chemotherapy, Day 0, Rachel experienced moderate levels of evening pain.
### Table 12

*Rachel’s Mean Symptom Scores*

<table>
<thead>
<tr>
<th>Symptom</th>
<th>All</th>
<th>Scores</th>
<th>Morning</th>
<th>Scores</th>
<th>Evening</th>
<th>Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>Range</td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Pain</td>
<td>2.24</td>
<td>1.33</td>
<td>1 - 5</td>
<td>2.30</td>
<td>1.31</td>
<td>2.17</td>
</tr>
<tr>
<td>Oucher</td>
<td>42.77</td>
<td>42.56</td>
<td>0 - 100</td>
<td>46.34</td>
<td>43.66</td>
<td>39.14</td>
</tr>
<tr>
<td>Fatigue</td>
<td>1.76</td>
<td>1.12</td>
<td>1 - 5</td>
<td>1.70</td>
<td>1.10</td>
<td>1.83</td>
</tr>
<tr>
<td>Worry</td>
<td>1.09</td>
<td>0.46</td>
<td>1 - 5</td>
<td>1.10</td>
<td>0.51</td>
<td>1.09</td>
</tr>
<tr>
<td>Nausea frequency</td>
<td>2.05</td>
<td>1.07</td>
<td>1 - 4</td>
<td>2.11</td>
<td>1.08</td>
<td>1.99</td>
</tr>
<tr>
<td>Nausea bother</td>
<td>1.56</td>
<td>0.83</td>
<td>1 - 5</td>
<td>1.63</td>
<td>0.95</td>
<td>1.49</td>
</tr>
<tr>
<td>Vomiting frequency</td>
<td>1.34</td>
<td>0.98</td>
<td>1 - 6</td>
<td>1.42</td>
<td>1.13</td>
<td>1.25</td>
</tr>
<tr>
<td>Vomiting bother</td>
<td>1.20</td>
<td>0.67</td>
<td>1 - 5</td>
<td>1.20</td>
<td>0.62</td>
<td>1.21</td>
</tr>
<tr>
<td>Retching frequency</td>
<td>1.07</td>
<td>0.38</td>
<td>1 - 3</td>
<td>1.06</td>
<td>0.33</td>
<td>1.09</td>
</tr>
<tr>
<td>Retching bother</td>
<td>1.09</td>
<td>0.46</td>
<td>1 - 5</td>
<td>1.10</td>
<td>0.54</td>
<td>1.07</td>
</tr>
<tr>
<td>Cortisol</td>
<td>8.195</td>
<td>3.61</td>
<td>1.89 - 24.896</td>
<td>8.198</td>
<td>4.02</td>
<td>8.193</td>
</tr>
</tbody>
</table>
Figure 39. Rachel's AM and PM pain over time.
Figure 40. Rachel's AM and PM Oucher over time.
Figure 41. Rachel's AM and PM pain by day since treatment administration.
Figure 42 shows Rachel's morning and evening Oucher scores plotted by the day following her chemotherapy administration. The patterns seen in figure 42 are very similar to that seen in Figure 41.

**Fatigue.**

Rachel's fatigue scores ranged from 1 through 5 with a mean of 1.76 ($SD = 1.12$). As shown in Table 12, there was a very small difference between her morning fatigue and her evening fatigue, with the evening scores being slightly higher. Figure 43 shows Rachel's morning fatigue pattern over the course of the study to have been highly variable. Her scores in the first month of the study showed a higher fatigue intensity than in the last 2 months. This pattern shows that, aside from 1 or 2 days, Rachel did not experience any relief from her fatigue in the first half of the study. However, in the latter half, she had some periods of consecutive days without fatigue. Figure 43 shows her evening fatigue scores over the course of the study. The pattern of her evening fatigue scores was much less variable than that in the morning. While she experienced high peaks in the first half of the study, these peaks were followed by consecutive days of moderate fatigue.

Figure 44 shows Rachel's fatigue scores plotted by days since chemotherapy administration. These two plots are very similar. Both the morning and evening figures show that Rachel scored her fatigue higher on Day 0, which represents the actual days on which she received her infusions. The following 2 days also represent periods of higher fatigue, as compared to the rest of the cycle.
Figure 42. Rachel's AM and PM Oucher by day since treatment administration.
Figure 43. Rachel's AM and PM fatigue over time.
Figure 44. Rachel's AM and PM fatigue by day since treatment administration.
**Worry.**

Rachel’s scores on the worry scale were consistently low and lacked variability. Her mean worry score was 1.09 (SD = .46). There was no difference between her morning and evening worry scores. Figure 45 shows Rachel’s morning and evening worry scores over the course of the study. Over the 84 study days, she scored herself as experiencing no worry, with the exception of three occasions on which she felt that she was a little worried and one occasion on which she felt the most worry possible. Figure 46 shows her morning and evening worry scores plotted by day since chemotherapy administration. The morning scores show a peak worry on Day 25, which just precedes the next cycle of chemotherapy and a slight peak on the actual days of infusion. Her evening worry scores show the same slight peak on the actual day of infusion and the first day following infusion.

**Nausea.**

Rachel’s frequency of nausea scores ranged from 1 through 4, with a mean of 2.05 (SD = 1.07). As shown in Table 12, her morning nausea scores and her evening nausea scores were close. Figure 47 shows her morning and evening frequency of nausea scores over the course of the study. Her morning scores show a high amount of variability in the first 10 days of the study, then a pattern of low variability over the following month. This period of low variability shows moderately high nausea levels with little relief. The morning nausea scores over the last 20 days of the study show that her nausea had decreased significantly with only two high peaks, which returned to the low valley by the following day. The pattern in her evening nausea frequency scores show very high variability across the first 50 days of the study and then a dramatic change to scores of low nausea intensity with low variability. In the final 20 days of the study, she reported no nausea in the morning or evening.
Figure 45. Rachel's AM and PM worry over time.
Figure 46. Rachel’s AM and PM worry by day since treatment administration.
Figure 47. Rachel’s AM and PM frequency of nausea over time.
Figure 48 shows Rachel’s morning and evening nausea frequency plotted by day since chemotherapy administration. Her morning nausea, on average, peaked on Days 2 and 3 post chemotherapy, with a moderate level of nausea intensity. Her evening nausea peaked on the days during which she was receiving infusions.

Rachel rated her bother by nausea, on average, at a relatively low level, with a mean of 1.56 ($SD = .83$). Table 12 shows a slight difference between her mean morning bother score and her mean evening bother score, with a higher morning level. Figures 49 shows her morning and evening bother scores over time. The pattern evident in these two figures is similar to the pattern of nausea intensity, in that Rachel was bothered more by nausea of higher intensity. She also seemed to be bothered more by nausea in the morning as compared to the evening.

**Vomiting.**

Rachel’s vomiting frequency ranged from 1 to 6, with a mean of 1.34 ($SD = .98$). As seen in Table 12, her morning vomiting frequency was higher than was her evening vomiting frequency. Figure 50 shows that the pattern to her morning vomiting was more variable and more intense than her evening vomiting. Figure 51 shows Rachel’s vomiting frequency plotted by day since chemotherapy administration. On average, the only peak day for morning vomiting was on Day 20. The peak day for evening vomiting was on Day 6.
Figure 48. Rachel's AM and PM frequency of nausea by day since treatment administration.
Figure 49. Rachel's AM and PM bother by nausea.
Figure 50. Rachel's AM and PM frequency of vomiting over time.
Figure 51. Rachel's AM and PM frequency of vomiting by day since treatment administration.
Rachel’s bother by vomiting ranged from 1 to 5, with a mean of 1.20 ($SD = .67$). Although there was no difference between her bother in the morning and the evening, Rachel was less bothered by vomiting than by nausea. Figure 52 shows her morning and evening bother by vomiting plotted over the course of the study. As with the nausea scores, the peak periods of bother correspond closely with the peak vomiting frequency. Rachel had very low evening vomiting bother scores in the last half of the study.

**Retching.**

Rachel’s retching frequency scores ranged from 1 through 3, with a mean of 1.07 ($SD = .38$). There was no difference between her morning and evening retching frequency scores. Figure 53 shows a very stable pattern, with the exception of two to three peaks, of no retching both in the morning and evening over the course of the study. As expected, Figure 54 shows that her retching did not peak on any one specific day post chemotherapy over the course of the study. Figure 55 shows morning and evening retching bother scores that are similar to the retching frequency pattern of low variability and no intensity.

**Sleep.**

Rachel’s sleep efficiency scores represent the degree to which her sleep was restful and restorative, from the time she fell asleep until the time she woke up. Her scores ranged from 25.3% to 94.3%, with a mean efficiency score of 75.05%. Figure 56 shows a pattern of extremely variable scores that tended to become more efficient as the study progressed. The pattern shows valleys of low efficiency that occurred at the end of the first and second months of the study.
Figure 52. Rachel's AM and PM bother by vomiting over time.
Figure 53. Rachel's AM and PM retching by day since treatment.
Figure 54. Rachel's AM and PM retching by day since treatment administration.
Figure 55. Rachel's AM and PM bother by retching over time.
Figure 56. Rachel's sleep efficiency over time.
Rachel's was a more efficient sleeper in her home than she was in the hospital. Figure 57 compares her home and hospital sleep efficiency scores. Her hospital sleep efficiency pattern was much more highly variable than that of her home pattern.

Figure 58 shows Rachel's sleep efficiency scores plotted by the day post chemotherapy administration. The pattern in this figure shows that, aside from a slight drop in efficiency on the day she received infusions, there was little variability over the remainder of the cycle and thus no trends related to when she was given her chemotherapy.

**Salivary cortisol.**

Rachel's morning cortisol levels ranged from 1.894 to 24.986, with a mean of 8.198 (SD = 4.02). Figure 59 shows Rachel's morning and evening salivary cortisol levels over the course of the study. Her morning cortisol levels show a pattern of high variability with moderately high peaks returning to low levels by the following day. Her cortisol level peaked extremely high during the last week of the study. Rachel's evening cortisol levels show a pattern that began with a very high peak in the first few days of the study but then gradually decreased over the next month. Her levels began to rise again over the last half of the study.

Figure 59 in conjunction with Figure 60, showing Rachel's morning and evening levels plotted by day post chemotherapy administration, indicate that there is no normal diurnal pattern of high morning levels turning to low evening levels. Table 12 shows that her mean morning cortisol level is almost identical to her mean evening level. Figure 61 shows that more of her evening scores are higher than her morning scores. This finding suggests that Rachel's HPA axis response is being stimulated by something other than her circadian clock. Indeed, this is evident when her morning and evening cortisol patterns are split into cortisol levels drawn while she is hospitalized and those drawn while she is at home.
Figure 57. Rachel's home versus hospital sleep efficiency over time.
Figure 58. Rachel's sleep efficiency by day since treatment administration.
Figure 59. Rachel’s AM and PM salivary cortisol level over time.
Figure 60. Rachel's AM and PM salivary cortisol level by day since administration.
Figure 6.1. Difference between Rachel's AM and PM salivary cortisol levels.
Table 13 shows her cortisol levels partitioned by the setting in which they were drawn. While Rachel’s home cortisol secretion appears to fit the diurnal pattern of high morning levels and lower evening levels, her hospital cortisol secretion pattern is the opposite. Rachel may have experienced more stress and thus secreted more cortisol steadily throughout the day while she was hospitalized.

Table 13

*Rachel's Cortisol Secretion By Time and Setting*

<table>
<thead>
<tr>
<th>Setting</th>
<th>Time</th>
<th>Range</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>Morning</td>
<td>3.992 – 24.986</td>
<td>8.872</td>
<td>4.41</td>
</tr>
<tr>
<td>Home</td>
<td>Evening</td>
<td>4.108 – 15.938</td>
<td>8.219</td>
<td>2.76</td>
</tr>
<tr>
<td>Hospital</td>
<td>Morning</td>
<td>1.894 – 16.853</td>
<td>7.712</td>
<td>3.72</td>
</tr>
<tr>
<td>Hospital</td>
<td>Evening</td>
<td>2.481 – 19.622</td>
<td>8.172</td>
<td>3.53</td>
</tr>
</tbody>
</table>

Returning to Figure 60 which shows Rachel’s morning and evening cortisol levels plotted by day post chemotherapy administration, her morning levels appear to reach a peak on post chemotherapy Days 2 and 14. Her evening levels appear to reach a peak on Days 0, 7, and 13.
Anxiety.

Rachel completed the Revised Children's Manifest Anxiety scale once each month while in the study. Table 14 shows that her Total Anxiety Score over the course of the study remained fairly constant, within one standard deviation below the normative mean for 7-year-old Caucasian girls.

Table 14

Rachel’s Scores on the Revised Children’s Manifest Anxiety Scale Over Time

<table>
<thead>
<tr>
<th>Scale &amp; Subscales</th>
<th>Day 01</th>
<th>Day 33</th>
<th>Day 73</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total anxiety</td>
<td>48</td>
<td>48</td>
<td>40</td>
</tr>
<tr>
<td>Physiological anxiety</td>
<td>11</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>Worry/Oversensitivity</td>
<td>7</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Social concerns/concentration</td>
<td>13</td>
<td>7</td>
<td>10</td>
</tr>
</tbody>
</table>

On the physiological anxiety subscale Rachel’s scores remained constant through the first 2 months of the study and then fell to more than one standard deviation below the normative mean. Her scores on the worry/oversensitivity subscale also fluctuated below the normative mean. Her scores on the social concerns/concentration subscale remained fairly constant within one standard deviation below the mean for the first two testing periods and then rose to within one standard deviation above the mean. Thus, Rachel’s scores on the
Revised Children’s Manifest Anxiety Scale reflect a constant state of average to slightly lower than average anxiety.

**Mood.**

Twice a day, using stickers with faces expressing the moods of happy, sad, lonely, or mad, Rachel rated how she felt at the time of data collection. Out of the three cases in the study, she was the only participant who completed and enjoyed this part of the diary. Abby and Michael transformed the mood rating by writing down words that reflected the type of day they had experienced. This type of sticker rating system may only be appropriate for the school-aged child in my study and not for a child of preadolescent or adolescent developmental stages. Rachel rated her mood as predominantly happy. On 87.86% of the data collection time points, she rated her self as happy. On 6.43%, 3.57%, and 2.14% of the data collection time points, she rated herself as sad, mad, and lonely respectively.

**Rachel’s Interview and Field Note Data**

Rachel did not like being interviewed with the tape recorder on. She also did not like answering my questions about treatment when she thought that I was trying to evaluate the emotional effect it was having on her. Without the tape recorder on, she would talk to me, at length, about many different things, but if she thought that I was trying to learn more about her worry or anxiety, she would not say anything further. Accordingly, much of the data used in this analysis was taken from field notes, which I wrote immediately following my data collection visits.

The trend of not wanting to talk about the emotional effects of treatment began very early in the study. A factor that could have accounted for her reticence was the death of a paternal aunt, with whom she was very close, about one year before her diagnosis.. Rachel
watched her aunt undergo many cycles of chemotherapy and eventually die a long and painful
death. She told me about her Aunt Phyllis very early on in the study. Aunt Phyllis was a nurse
and Rachel kept her aunt’s stethoscope with her at all times. As a result of her experience
watching her aunt die, Rachel’s parents decided not to tell her that she had cancer. They felt
that the knowledge that she too had cancer would worry her so much that she would not be
strong enough to fight the cancer and endure her own treatment. They asked me not to
mention the word cancer to Rachel, but that I could talk about chemotherapy and treatment.
They had told Rachel that she had “a disease in her blood that was making her very sick and
that she was going to get chemotherapy to treat that disease in her blood.” Rachel was not
allowed to watch the Charlie Brown movie on the pediatric unit, that all children with cancer
see in order to understand many issues about childhood cancer and treatment. Children on the
pediatric oncology unit often talked about the Charlie Brown movie, which they are shown
within the first week after diagnosis.

Two weeks into the study it was clear to me that Rachel had privately come to
understand that she had cancer, and that her parents did not want her to know she had it or to
talk about it. She would ask me questions about the other two children in my study, what they
had wrong with them, and why they were getting chemotherapy. On February 21, 1999,
following her critically ill period in which she was admitted to the pediatric intensive care
unit, Rachel became very upset with me and the questions I was asking her. She would not
tell me why she was so upset, only that something very bad was bothering her and she would
not tell anyone what it was. Rachel’s behaviors changed at this point. A previously very
independent child, who enjoyed going to the playroom and other unit activities,
unaccompanied by her parents, she suddenly became very attached and demanded that they
be present in her hospital room at all times. Rachel cried frequently and clung to her mother's side. She frequently requested that her mother lie in her bed with her. Jeanne, Rachel's mother, was extremely upset by this behavioral change in her daughter. She asked me what I thought might be causing it. I told her that I thought that Rachel had come to understand that she had cancer, like Aunt Phyllis.

During Rachel's first discharge home, Jeanne spent some time talking to Rachel about the childhood cancer that she had and how it differed from that which her Aunt Phyllis had. She tried to get Rachel to verbalize her fears about her cancer and her treatment, but was not successful. Rachel continued to enjoy being in the study and filling out the sticker diary, collecting saliva samples and wearing the Actiwatch, but she was very adamant about not talking to me about the effect that the treatment was having on her emotions. She became especially sensitive to the term, worry, and would become very angry whenever her parents, nurses, or I asked her about her about why she seemed to be upset and anxious.

The following analysis is a combination of data collected during tape recorded interviews, and interviews occurring during conversations that were later recorded through the use of field notes.

Study Day 4 — Day 36

The content in this first analysis period centered around the notion that Rachel did not want to talk about treatment and the effect that it is having on her. More specifically she did not want to talk or be asked about her worries or fears. She stated multiple times that she was not worried.

When Rachel first heard that she was going to get chemotherapy, she said that she did not like the idea. Rachel did not like being in the hospital at this point in time. When asked
what she would wish for if she had three wishes she stated in this order: to get tickets to Disney World, get out of the hospital, have a rose garden.

The symptom that bothered her the most throughout this period was pain. She experienced moderate to severe pain in her stomach, back and head. Rachel told me that the pain changed throughout the day, sometimes getting better at night. The pain was bothersome to Rachel and she wished that it would go away. Rachel’s pain was centered mainly around her stomach. She was having difficulties with her liver and gastrointestinal track and this brought severe pain. She would hear the physicians and her parents change their minds daily regarding what the problems were related to.

Rachel talked to me about what she felt it would be like for other children to get chemotherapy. Some of her replies were:

... You can’t feel anything. It’s not bad at all. It might bother some kids, but it doesn’t bother me. It might bother younger kids. Yeah. You would have to get stuck and stuff. And bone marrow – hate. You’ll cry! I didn’t cry. I don’t cry much anyway. Cause I’m not a baby! She thought that other kids should be told not to “be afraid. Be brave.”

Rachel told me that the first feeling that she experienced with chemotherapy was being sick to her stomach. However this feeling doesn’t happen right away and it is not the worst part of chemotherapy.

Rachel was worried very early in treatment about losing her hair. Her parents had talked with her about the fact that her hair would fall out, but the reality set in when she began noticing the other children on the unit with no hair. At this point in her treatment Rachel had already lost the majority of her long blond hair.
It was at this point in her treatment cycle that I first noticed that Rachel did not like talking about being worried or anxious. When I asked her about the word worry she replied that “I said I don’t like that word anyway. I hate it. God! I hate getting chemo, well I don’t. I just don’t like to talk about it.”

**Study Day 37 – Day 64**

Rachel and I talked a lot about her first, very brief discharge home. She described how sick she had been at home and that she had thrown up six times. Rachel preferred throwing up at home to throwing up in the hospital as it was more comforting at home and she had more familiar objects around her. She told me, “I’ve been throwing up at home for about 3 years. It is better.”

I was attempting to use Rachel’s symptom diary, which she enjoyed completing, to see if I could use it as an elicitation device. I asked her about one of her rare mood ratings that was not rated as happy. I asked her why she rated herself as mad for that particular day. She replied, “... I just didn’t feel that, that’s why. You can just put it if you want and nobody has to ask you why.”

When asking Rachel about some of her other symptoms, she started telling me about a girl named Sherry whom she had gotten to know on the unit.

If this girl named Sherry was in here, she would feel bad everyday because her first chemo didn’t go well. She would say that she didn’t want to get chemo again. ‘Cause they had to take out part of her intestine, well part of her lungs. The doctor might have to take out my gall bladder. I hate that. I don’t want my gall bladder taken out.

Again I asked Rachel what she would want to tell other kids who are about to get chemotherapy. She replied, “Don’t be so scared. ‘Cause you’re not supposed to be scared.”
Rachel requested that her mother always be present when we talked together. This appeared to make her feel more secure. Rachel felt that the first and third chemotherapy cycles went pretty well but the second one was not as easy. She said that she and her parents thought that this third cycle would be like the first one but it was not as bad. This was a big relief to her.

She said the third one went well, but it made her feel sleepy. She told me that the sleepiness makes it hard to do school work. Even though she was always a very good student, she told me that she did not want to do her school work anymore. She liked school before because she was in the classroom with everyone else. It is different now because she is home by herself.

Vomiting: she did not experience much vomiting with the third round of chemo. The second round brought about more vomiting.

Nausea: she said that her appetite was very good she was eating like a horse. With the first and second round she said that every time she ate or drank something she threw it up. With the first round she told me that she did not eat for 19 days.

Pain: had gotten a lot better. When the pain was present it was very bothersome. She did not want to do anything when the pain was bad.

Hair loss: she feels that her hair is starting to grow back now and that she likes having short hair.

Worry: she still does not want to talk about it, but felt that it had not gotten any better since she has been at home. The worry is worse during the day. It helps when her Mom lets her sleep downstairs. This is because when she is up in her room she worries more. She likes
more light on now. She use to sleep without a nigh light and now she always leaves on her lava lamp. This helps with not being scared. She finally refused to talk about worry any further.

When asked for advice to give another child her age she said she would tell them that chemotherapy will make them feel bad. But it is making her well. There were times when she felt like she did not want to get chemotherapy anymore (during the first cycle).

One story that she focused on was an experience when the physician jerked her nasogastric tube out without warning her or giving her any sedation. This worried her. Rachel talked about her first experience of returning to school since she was diagnosed. She went to the school playground for an Easter egg hunt.

I asked Rachel about the worst thing about treatment. She said that it was that she got sick to her stomach and had her tube pulled without any warning. She said that she would rate all of her symptoms (vomiting, sleepiness, pain and losing her hair) as all equally bad. I asked her what was the best thing about getting chemotherapy and she told me that it was going to help her get better.

Rachel told me that one of the things that had changed for her since she had gotten home was that she did not like to sleep alone in her room anymore. She said that it was not that she was scared, it was just that she did not like the dark anymore and she preferred to sleep on the floor in her mother’s room.

When I asked Rachel about how she felt about her next cycle of chemotherapy she replied:
"Now I have three things to think about. If I want to put a port (internal central line) and... I don’t know about a port but my Aunt Phyllis knows about a port. But I don’t think I want anything. But I don’t like when they stick it in my skin.”

I asked Rachel if there was something that she wanted to teach nurses about how to give chemotherapy to kids. She replied, "No. Unless it’s a different kind of chemo. If there’s a stronger kind or... Stronger like my Aunt Phyllis got... Well, I don’t need a stronger kind of chemo.”

Finally, I asked Rachel how she felt about being in the study. She said that she liked the stickers and prize day, but that she did not like the questions. I asked her to tell me specifically which questions she did not like. She replied, "Worry. I don’t want to hear it or say it again? I’m not. I just don’t like to hear the word or talk about it! I just hate it!

Summary and Conclusions-Within Case Generalizations

Rachel’s symptom experience seemed to be characterized by fear. Her self-report data illustrated moderate to high levels of most symptoms which gradually decreased to show a pattern of habituation. Her qualitative data revealed that this habituation seemed to occur in a context of fear surrounding the issue of her knowledge of her diagnosis.

Cross Case Interpretations

The cases of Abby, Michael, and Rachel were very distinctive and each demonstrated a unique symptom experience. There are important continuities across all three cases that can be isolated as well as important dissimilarities.

Continuities.

All three children described how each cycle of chemotherapy brought about a different focus symptom, or worst symptom. They all felt that they could not isolate just one
symptom, across their initial treatment experience which they would describe as the most troublesome. Along the same lines, an important theme was that the symptom experience, for these children, was more clearly characterized by how all of the symptoms appear and were linked together rather than how individual symptoms effected them.

All three children in this study seemed to find meaning in their symptom experience based upon prior experiences with relatives with cancer. In all three cases, watching a relative suffer through the side-effects of treatment made it more difficult for them to habituate to their own symptom experience.

Worry was a central concept across all three cases. Abby used worry as a central method to explain her symptom experience. Worry remained a very strong thread throughout her symptom experience. Michael’s concept of worry was based upon the notion that he did not want his parents to be worried about him. He seemed to feel that if he expressed or relayed any symptoms to me, his mother would respond with worry. Thus he consistently denied reports of any symptoms in the self-report data. Rachel’s concept of worry was based upon her refusal to let anyone know the reason why she was so worried. While she conceded to the fact that she was worried, she refused to discuss the reasons why.

The older two children, Michael and Abby, both talked about how unprepared they were for the sensations they experienced throughout the treatment period. However, Abby provided the caveat that even if she was told how bad it would be, she would not have really understood it until she was in the midst of it herself.

Dissimilarities.

One of the main dissimilarities in the symptom experiences of all three cases was related to how central symptoms were to the treatment experience for these children. For
Abby. symptoms, as expressed through more abstract concepts, were a central focus. For Rachel and Michael, their treatment experience was not characterized by their response to their symptoms.

A second important area in which the three cases were dissimilar was in relation to how they responded to their symptoms over time. Abby’s pattern of response to her symptoms seemed to be one of increasing distress. She did not habituate to her symptoms over time, and in several cases, her symptom experience became more intense. Rachel’s symptom experience was intense at the beginning of the treatment period, but then she showed a pattern of habituation in which all of her symptom patterns decreased over her time in the study. Michael’s symptom experience did not seem to alter throughout the study. He began by expressing a lack of symptoms and this continued throughout his time in the study.
CHAPTER FIVE

DISCUSSION

Introduction

In this chapter, I discuss the findings of this study in relation to the substantive concept of symptom distress and the purposes set forth at the beginning of the study. In addition, I discuss the study findings in relation to the methodological issues that arose from studying symptom distress in children and adolescents and the implications these issues have for future research. Finally, I discuss the significance of the findings in relation to the practice of nursing.

Substantive Issues

In this study, symptom distress was defined as the physical or mental anguish or suffering that resulted from the experience of symptom occurrence, the perception of feeling states, or both (Rhodes & Watson, 1987). I attempted to keep an open mind regarding what the symptom experience might mean to the children in this study, and I feel that this definition fits closely with the symptom experiences that emanated from the quantitative and qualitative data in this study.

My central purpose was to explore the phenomenon of symptom distress from the perspective of children and adolescents undergoing chemotherapeutic treatment for cancer. I designed and conducted a study that allowed me to examine the day-to-day symptom
experience of children to elucidate patterns of symptom distress that may have emerged in response to the treatment. Overall, the combination of biobehavioral, self-report, and narrative accounts of the symptom experience were essential to attempt to grasp different facets of the experience.

The overall research question I posed was: What is the profile of symptomatic response in children and adolescents produced as a result of the side effects of chemotherapeutic treatment for a solid tumor or acute myelogenous leukemia? This overall question was then broken down into three sub-questions, which are presented below with a discussion of the findings as they relate to each sub-question.

The first sub-question I examined was related to how the individual biobehavioral and self-report symptom patterns contributed to the profile of symptom experience over the initial treatment period. In Abby’s case, the biobehavioral and self-report symptom patterns are an essential part of her symptom experience. I was able to see, by graphing the individual symptom variables over time, the development of increasingly intense symptoms and Abby’s lack of habituation to her individual symptoms.

Other researchers have described a similar response to chemotherapeutic treatment for childhood cancer. Several scholars have found that many emotional and behavioral difficulties associated with the aggressive treatment regimens are related to adaptation to the disease, compliance with therapy, and eventual efficacy of the treatment (Balı et al., 1997; Burish, Carey, Krozely, & Greco, 1987; Dolgin, Katz, Zeltzer, & Landsverk, 1989; Gorfinkle & Redd, 1993; Hubert, Jay, Saltoun, & Hayes, 1988). Hockenberry-Eaton and her colleagues (1994) also found that some children had such difficulty coping with their symptoms that
they displayed physical, psychological, and behavioral manifestations that accumulated across the treatment trajectory.

For Abby, the symptoms became the central focus in her life, to the exclusion of school, friends, and leisure activities. As a result, Abby said she had lost her identity. Kerry (1990) also reported on the centrality of side effects of treatment to children with cancer and found that adolescent survivors reported that, as a result of the distressing side effects, they would refuse treatment if their cancer were to recur.

The increasing intensity and bother of Abby's self-report and biobehavioral symptom patterns, in combination with the mounting worry and anxiety that arose from the qualitative data, indicate that Abby developed anticipatory symptom distress. That is, much of the distress she experienced in the latter half of the study was related to her anticipation of, and conditioned responses to, the symptom experience in the first half of the study. Researchers, investigating the concept of anticipatory nausea and vomiting (ANV) in adults and children receiving chemotherapy, found that the onset of ANV usually occurs by the fourth or fifth course of treatment (Pickett, 1991). Abby's anticipatory symptom distress began to appear by the fourth course of treatment.

Certain variables have been identified as strongly predictive of which patients will develop ANV. These variables include treatment with a drug regimen of high emetogenic potential, symptom and psychosocial distress, mood disturbances, and limited ability to cope with treatment stress (Andrykowski, Redd, & Hatfield, 1985). Although some researchers have reported contradictory findings, some chemotherapy-associated variables are the emetogenicity of the chemotherapy they receive, sweating, feeling warm or dizzy following their last chemotherapy, female gender, and high trait-state-anxiety (Andrykowski & Redd,
An important contribution to the symptom experience of the children in this study was the lack of predictability in the way the symptoms would appear. For Abby, there were no clear patterns in the biobehavioral and self-report data that would relate to the regularity with which the symptoms appeared across the days following each cycle. Thus, it was difficult for Abby to predict with each cycle which symptom would be the most bothersome, when it would appear, and how long would it last. Abby’s narrative accounts of her symptom experiences were often characterized by her feelings of lack of control over her symptoms and her wish to know how she would feel the next day. She expressed feelings of extreme vulnerability and loss of control. Similarly, Abby, Michael, and Rachel also felt that each cycle of chemotherapy furnished a different symptom as the central symptom of distress, making it difficult for them to predict how they would feel following each cycle.

Pain appears as a prominent symptom for all three cases, both in the self-report and narrative data. Abby’s and Rachel’s pain scores remained moderately high throughout the study. This pain came from a multitude of sources, such as procedures, bone pain, and stomach pain. In addition, the pain experience was intricately linked with other symptoms of treatment such as nausea, sleep alterations, and fatigue. For example, Abby talked a lot about how her nausea and vomiting brought about much stomach and epigastric pain. The phenomenon of one symptom being associated with increasing levels of another symptom illustrates the constellationary mechanism of symptom distress. Studying individual symptoms over time is not sufficient, rather how all of the potential symptoms occur together to influence the symptom experience.
Other examples of symptoms, which seem to have exponential or building effects on one another, are sleep alterations, pain, nausea, and stress. Mabe and colleagues (1991) found a similar association between symptoms of treatment, but they focused on how the physical symptoms seemed to bring about novel emotional symptoms such as depression and anxiety. They found a positive correlation between the children's distress response, which manifested itself in depressive and anxious symptoms and the duration of physical symptoms.

Some researchers have found that the most distressing symptoms to children undergoing cancer treatment are the symptoms associated with physical changes for the child (Chekryn, Degan, & Reid, 1987). This finding is not apparent in the symptom experience of the children in this study. Though all three children talked about the experience of losing their hair and losing weight, these events may not be associated with distress. I observed and listened to their stories about hair loss from the time before any loss of hair to the time at which most of their hair had fallen out. Each child seemed well prepared for the loss of his or her hair. For Abby, this finding is somewhat anomalous. For all other symptoms besides hair loss, if Abby spent too much time thinking about the coming symptom and how she would respond to it, she developed very high distress. However, regarding her hair loss, the time spent wondering and waiting made the actual occurrence more acceptable.

The second sub-question I examined was how the children describe and ascribe meaning to their responses to symptoms. As Abby talked about her symptom experience during the study, while apparently reconstructing and interpreting her experience for me, Abby was in a constant quest for not only the meaning her response held for her but also how she might come to understand or predict her future responses based upon her interpretations. Kameny and Bearison (1999) also found that adolescents with cancer use narratives as a
conscious activity in which they search for a reinterpretation of past, present, and future events. As I listened to Abby talk about her response following each cycle of chemotherapy. her constant movements in time, either before the current cycle or after the current cycle, or before treatment and after treatment, showed she was apparently searching for some way to characterize her response. One central metaphor Abby used to express her fright at her response was manifested in statements such as “if I couldn’t fight the treatment how could I fight the cancer” and “getting the cure is worse than getting the cancer.”

The third sub-question I examined was regarding the confluence among the symptom patterns that emerged from the biobehavioral, self-report, and narrative accounts of the treatment experience. The biobehavioral and self-report symptom patterns that developed for Abby had a large influence on her symptom experience. Abby’s profiles for individual symptoms such as pain, nausea, and vomiting showed a curve that demonstrated moderate to high intensity levels that either increased over the period of the study or remained at a constant moderate to high level. In conjunction with these profiles, Abby’s narratives about her response to the symptoms of treatment and the meaning that the symptoms had for her demonstrated the development of increasing levels of worry, anxiety, and depression during the study. This emotional response, which seemed to spiral upward, caused Abby to question whether she could withstand the treatment. As well, she developed secondary symptoms, such as anticipatory nausea and vomiting and acid reflux, in response to her emotional outcome.

In Abby’s case, her self-report and narrative data seem to fit closely in illustrating her increasing symptom intensity over time. Abby’s salivary cortisol levels demonstrate some concordance with her narrative data. Her mean morning cortisol levels are fairly close to the
norms stated for children 8 to 18 years of age (Kiess et al., 1995), but her mean evening
cortisol levels are three times higher than are the norms stated for this age group. Thus,
Abby’s salivary cortisol levels demonstrate that she is maintaining a higher than normal level
of the stress hormone in her saliva as the day progresses in contrast to the normal pattern of
decreasing levels over the day. This finding fits very closely with the stress that Abby
describes in her narrative accounts. Abby described, in great detail, her difficulties with sleep
and the anxiety this brought about. However, her Sleep Actiwatch data demonstrate she is a
fairly efficient sleeper. This discordance may be a methodological issue.

There is very little confluence between the self-report and biobehavioral data of
Michael and Rachel and their narrative data. This finding may be a methodological issue.

A central issue across all three cases is whether chemotherapy treatment for children
is more easily tolerated as an outpatient or an inpatient. The cases of Michael and Rachel,
both inpatients, talked about how they would rather have their chemotherapy administered to
them in their homes. However, for Abby, the isolation, lack of control, and unpredictability
of the symptoms are worsened by the family’s attempts to care for her at home.

Methodological Issues

There are many methodological issues inherent in studying symptom distress in
children. Globally, because many symptomatic responses to cancer treatment are subjective
sensations (e.g., pain, nausea), there are no direct physiological or behavioral empirical
indicators to indicate their severity. In addition, with the exception of pain instrumentation,
there are no developed and reliable instruments available to use with this population.
Although symptom distress instruments and instruments to measure individual symptoms
such as nausea, vomiting, and bother are available for adult populations, the developmental
needs of the child and adolescent make these instruments inappropriate for use with these two populations.

The children used verbal, behavioral, physiological, and emotional representations of their symptom experience. Each of these modes of expression was not useful for each child. The self-report and biobehavioral methods appeared to be most useful for the school-aged children in this study. These two children were particularly resistant to audio-taped structured interviews. However, I was able to get them to express their symptom experience verbally when I used less structured conversational techniques. I obtained a wealth of information by posing questions and listening to the children as they were playing a board game. The adolescent in the study was particularly expressive using the verbal mode. She was an adept abstract thinker and was able to place her symptom experience into larger response structures.

The symptom diary was designed as a sticker system in which each child was to place a quantity of stickers that reflected the intensity of that symptom next to the symptom they were experiencing. Whereas Rachel received the sticker system very well and consistently used the stickers throughout the study, Michael and Abby quickly adapted the diary to a pen or pencil system. The second part of the diary requested that the child rate his or her mood using stickers with faces depicting the moods of happy, sad, lonely, and mad. Again, Rachel was the only participant who rated her mood twice a day by the system set forth at the beginning of the study. Michael and Abby adapted this section by writing in their own adjectives to describe the type of mood they were experiencing.

The use of the Sleep Actiwatch to measure sleep efficiency seems problematic, as the sleep data scores do not often fall in concordance with that obtained from the narrative data. There are many possible reasons for this low concordance. Theoretically, the Actiwatch
measures the amount of movement during sleep. Thus a child may lie awake, being very still and yet have a high sleep efficiency score. In addition, the behavioral manifestation of sleeping with another person in the same bed may have affected the validity of the data obtained. However, the Sleep Actiwatch measures the amount of the child’s movement while he or she is in bed.

The ability to identify the symptom distress of a vulnerable child may be an important part of the quest to make childhood cancer treatments more efficacious at higher levels of toxicity. This study is a first step in isolating how the process of symptom distress develops over time. The next level of study would be to follow a larger cohort of children, over the same time span, using similar measures to elucidate a closer image of when the distress first begins to increase.

In addition, I would like to extend the description of the surviving children from this study, by contacting them 6 months and 1 yr following treatment to assess their recollections and the meanings that the symptom experience has for them at these distant time points.

Another important future research consideration would be to include parent data in the documentation of the symptom experience. Mabe and colleagues (1991) found that children’s distress response manifests itself in depressive and anxious symptoms, which they positively relate not only to duration of physical symptoms but also to parental distress.

Implications for Nursing Practice

The concept of symptom distress is a central part of the quality of life of children undergoing cancer treatment. Pediatric oncology nurses interested in how treatment for cancer affects the daily lives of the children for whom they provide care need to take a closer
look at how the children’s responses to their symptoms affect the larger area of quality of life. The results from this study have some important implications for nursing practice.

The manner in which children express symptom distress is complex and multifaceted. In this study, the three children varied in the manner in which they showed their distress. The children used verbal, behavioral, physiological, and emotional representations of their symptom experience. All of these expressions were not useful for each child. Thus, practitioners need to be adept in a battery of methods to allow for the expression of symptom distress. In addition, various personal variables of the child and his or her family seem to affect how they are able to express their distress. Gender, age, personality, family history of cancer, and culture were all variables that seemed to alter the manner in which symptom distress was most effectively expressed. Whereas certain children may be more open to discussing their symptom distress, and thus may appear to be experiencing higher levels of distress, other children may have more difficulty with expression and may need more support to help bring it to the surface.

In documenting Abby’s symptom experience over time, there are indications that she developed high levels of distress in response to her symptoms. Indeed this distress, at times, was so great that she expressed a desire to stop treatment. The process of developing distress in reaction to symptoms may be a phenomenon that moves and amplifies over time. Abby began treatment with clear worries about how she was feeling. These worries transcended themselves into anxiety, depression, and loneliness. Nurses working with children undergoing chemotherapeutic treatment for cancer need to be aware that symptom distress may increase over time as treatments continue. Thus stress and coping interventions need to be placed strategically throughout the treatment period, not just at its initiation.
Symptom distress in children is a constellatory mechanism that is multifaceted. The reaction of any individual child to his or her treatment will most likely depend on the combination and pattern in which the symptoms present themselves over time. Though attempting, with supportive measures, to control individual symptoms is an important part of assisting the child through their treatment protocol, it will also be necessary to assess continually how the pattern of symptoms is developing for the child and to intervene at the appropriate level.

A very important finding from this study is that children may attach a wide range of meanings to the symptoms that come out of their treatment. Some of the meanings attached to the symptom experiences of the children in this study were fear of dying, feelings of loss of identity, feelings that the body was falling apart, and that symptoms are a duty or obligation. The meaning that an individual child attaches to his or her symptoms appears to have a large impact on the amount and manner in which they express their distress. For example, symptoms for Rachel appeared to remind her of her aunt. Because her aunt had died, the symptom meaning for Rachel was one of fear.

Practitioners working with children with cancer need to be adept in accessing, over time, the meaning that an individual child has attached to his or her symptom experience. Ongoing assessment enables the practitioner to get a better understanding of how distressed the child may be, the manner in which he or she may best express distress, and how to intervene.
REFERENCES


aversions in pediatric oncology. In W. Breitbart & J. C. Holland (Eds.), Psychiatric
aspects of symptom management in cancer patients (pp. 129-146). Washington, DC:
APA.

D. Franklin, D. B. Allison, & B. S. Gorman (Eds.), Design and analysis of single-case
research (pp. 159-214). Mahwah, NJ: Erlbaum.

Symptom distress in cardiac transplant candidates. Heart & Lung. 21, 434-439.


doctoral dissertation, Yale University.

Medicine. 329, 1790-1796.

on neuroendocrine responses to challenge and threat in infancy and childhood. In M.
Lamb, A. Brown, & B. Rogoff (Eds.), Advances in developmental psychology (Vol.

reactivity because of rapid habituation of the adrenocortical response. Developmental
Psychobiology. 22, 221-233.


Hockenberry-Eaton, M., Hinds, P. S., Alcoser, P., O’Neill, J. B., Euell, K., Howard, V., 
Journal of Pediatric Oncology Nursing, 15, 172-82.

Nursing assessment and intervention. Oncology Nursing Forum, 17, 575-584.

of North America, 23, 475-497.


adjustment to recurrent breast cancer. Social Science & Medicine, 41, 69-76.


and mood among persons receiving radiotherapy. Cancer Nursing 14(2), 71-78.


Press.

Journal of Clinical Oncology, 12, 608-616.

stimuli controlling it. In. T. R. Kratochwill & J. R. Levin (Eds.), Single-case research
design and analysis. New directions for psychology and education (pp. 15-40).

Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.). Newbury Park,
CA: Sage.


Quality of life assessment in a home care program for advanced cancer patients: A


diagnosed children and adolescents with acute myeloid leukemia: A children’s cancer


vomiting in women receiving cyclophosphamide, methotrexate, and 5-FU adjuvant
chemotherapy for breast carcinoma. Cancer Treatment Reports, 66, 1601-1604.


perceptions of acute pain. Qualitative Health Research, 6, 184-201.

Woodgate, R., & Kristjanson, L. (1996). “Getting better from my hurts”: Toward a model of

to adopt a meaning-centered approach. Journal of Pediatric Oncology, 15, 3-12.


Psychology, 13, 101-112.

Wright, G., & Alpern, G. (1981). Variables influencing children’s cooperative behavior at the

Seminars in Oncology Nursing, 11, 289-297.


CONSENT FORM

INFORMED CONSENT FOR RESEARCH
PATTERNS OF SYMPTOM DISTRESS
DURING THE INITIAL TREATMENT
PERIOD IN CHILDREN WITH CANCER
MINOR
IRB # 1443-98-9

Your child has a newly diagnosed solid tumor (cancer) for which he/she is being treated with chemotherapy. Nurses at Duke are doing a research project to study how children feel while getting cancer treatment. The purpose of this research study is to learn more about how children feel and deal with getting chemotherapy. Your child is eligible to participate in this study. We are asking you to allow your child to be in this research study because your help is needed to identify what types of feelings (pain, nausea, worry, tired, happy) children have while getting chemotherapy.

Your child will be asked to do four things: (1) Fill out a sticker diary, twice a day, which will keep track of the type of feelings your child has. The sticker diary will take your child approximately 10 minutes in the morning and 10 minutes in the evening each day to fill out. (2) Provide a small amount of saliva, by spitting into a straw twice a day to let us measure the amount of cortisol (a hormone, the production of which may be related to stress) contained in it. The saliva collection will take about 5 minutes each day to complete. (3) Sharron Docherty, R.N., the Principal Investigator of the study, will meet with your child once every 2 weeks and ask your child some questions about how your child is dealing with the feelings your child is having. She will use a tape recorder to tape your child’s answers to these questions. This will take approximately 20 minutes once every two weeks. (4) Wear a type of wrist watch at night which will tell us how well your child sleeps as another indicator of stress.

We will ask your child to do these four things every day for 3 months while your child is getting cancer treatment. While your child is in the hospital he/she will be asked to fill out the sticker diary and give a saliva sample at 10:00 in the morning and 6:00 in the evening. Your child will be asked to put the wrist watch on once he/she is ready to go to sleep for the night. Sharron Docherty, R.N., the Principal Investigator will be present at the hospital to help your child complete these tasks. Once your child goes home he/she will be asked to fill out the sticker diary and give a saliva sample at 10:00 in the morning and 6:00 in the evening, and then wear the wrist watch to bed at night. Once your child returns to school he/she will be asked to fill out the sticker diary and give a saliva sample before he/she leaves for school and then at 4:00 in the afternoon. If your child requires help to complete the sticker diary and the saliva sample Sharron Docherty, R.N., will drive to your home each day and help your child. If your child can do these things by himself/herself, Sharron Docherty will drive to your home once a week to pick up the diary and the saliva samples. She will also come to your home once every two weeks to ask him/her the tape recorded questions.

No extra visits to the hospital or clinic will be asked of you or your child if you decide to take part in this study. There will be no extra costs to you or your child if you decide to take part in this study.

Initials of Parent
Sometimes things happen to people in research studies that may make them feel bad. These are called risks. There are no known risks in this study. People also may have good things happen to them because they are in research studies. These are called benefits. There will probably be no direct benefits to your child from your child’s participation in the study. However, your help in this study may help nurses and doctors better understand the stresses that children receiving cancer treatment may feel, and thus be better able to deal with them.

Participation in this study is voluntary. No compensation for participation will be given. However, in order to help ensure your child’s continued participation during the three months of the study, your child may choose to accept a small gift each week (such as a toy or book), worth about $5.00 that will be provided by the study Principal Investigator. You are free to withdraw your consent for your child’s participation in this treatment program at any time without prejudice to subsequent care. Refusal to participate will involve no penalty. If your child does not take part in or withdraws from the study, your child will continue to receive care.

A record of your child’s progress on this study will be kept in a confidential form at Duke Medical Center. Only the nurses doing this study will know your child’s answers. No information by which your child can be identified will be released or published except as required by law.

Immediate necessary care is available if an individual is injured because of participation in a research project. However, there is no provision for free medical care or for monetary compensation for such injury. Further information concerning this and also your child’s rights as a subject in a research study can be obtained from the Hospital Risk Management Office, (919) 681-7811. Further information on this study can be obtained by contacting the Ms. Sharron Docherty, RN, MSN at (919) 681-7811 or Dr. Phillip Rosoff at (919) 681-7811.

“I have read all of the above, had the opportunity to ask questions, and willingly give my consent for my child’s participation in this study. Upon signing this form, I will receive a copy. If my child is between 6-12 years of age, s/he has had this study explained to him/her.”

Parent/Guardian Signature

Date

Patient Signature (if over 12)

Date

Person Obtaining Consent

Date
## APPENDIX B

### SAMPLE DIARY PAGES

**Morning**

<table>
<thead>
<tr>
<th></th>
<th>1 not at all</th>
<th>2 a little</th>
<th>3 some</th>
<th>4 alot</th>
<th>5 most possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tired</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worried</td>
<td></td>
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</tr>
</tbody>
</table>

**Mood**

**Comments:**

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How much time has your stomach hurt?

NONE of the TIME
A LITTLE BIT of the TIME
QUITE A BIT of the TIME
ALL of the TIME

Date ___________
Subject # ________

Being sick to my stomach was ...

as bad as it could be
not bad at all
How many times did you throw-up?

0
1
2
3
4
More than 4

Throwing-up was...

as bad as it could be

not bad at all
How many times did you try to throw-up and nothing came out?

0
1
2
3
4
More than 4

When I tried to throw-up and nothing came out, it was...

as bad as it could be

not bad at all
<table>
<thead>
<tr>
<th>Morning</th>
<th>Evening</th>
</tr>
</thead>
<tbody>
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</tr>
<tr>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Date ___________________
Subject # ____________

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<table>
<thead>
<tr>
<th>Mood</th>
<th>Type of Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comments:</td>
<td></td>
</tr>
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</table>

Date ________  Subject # ________

<table>
<thead>
<tr>
<th>1 not at all</th>
<th>2 a little</th>
<th>3 some</th>
<th>4 alot</th>
<th>5 most possible</th>
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<tr>
<td>Tired</td>
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ABV'S SYMPTOM EXPERIENCE FRAMEWORK

APPENDIX C