Living with Life-threatening Illness: An Inquiry into Children's Experience of Cancer

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Living with Life-threatening Illness:

An Inquiry into Children’s Experience of Cancer

Presented to the Faculty

of the Psychology Department

McAnulty College and Graduate School of Liberal Arts

Duquesne University

in partial fulfillment of

the requirements for the degree of

Doctor of Philosophy

by

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Living with Life-threatening Illness: An Inquiry into Children’s Experience of Cancer

Submitted in partial fulfillment of requirements for the degree of Doctor of Philosophy

November 29, 2003

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Abstract

Previous studies concerning children living with illness have been limited by (a) a narrow focus on the child’s cognitive development, (b) reliance on sources outside of the child’s experience, (c) reliance on methods based on the language and quantitative modes of measuring used by adults rather than the experience of the child, (d) models that emphasize methods of control in coping, and (e) a tendency to pathologize the responses of the child.

In contrast, the current study involved speaking directly with school-aged children living with a diagnosis of cancer. The qualitative method developed for this study involved a two-fold approach, coupling drawings with interviews. This approach involved participants in a natural activity that allowed them to ”open up” by showing their world, and then narrating the story “behind” the pictures. This approach led to significantly more elaboration and attention to their individual experiences. Recommendations are made for using the method of combining drawings and interviews both in research and in the ongoing care of children living with illness.

Results indicate that these children do not fundamentally identify themselves with having cancer, describing themselves as “normal” kids, rather than as “patients.” Participants described varying ways of “getting through the tough times,” including distraction and the support of family and friends. Most participants identified the “worst” part of having cancer concretely in terms of painful procedures or the unfamiliar environment of the hospital. Though participants dreaded painful procedures, each spoke of the care with which they were treated by the doctors and nurses who performed them. Participants sought to give meaning to their painful present and uncertain future by strengthening relationships or seeking to use their experience to help others.
The prevailing metaphor in current literature portrays the patient and doctor as soldier and general engaged in battle. Here a new metaphor is introduced involving medical staff as guides who lend their expertise in leading patients along an uncertain and often treacherous path. In this new metaphor, patients are not abandoned if they begin to “lose the fight,” but are instead guided through to the end of their journey.
What do you see when you’re looking at me?
Simply the girl in bed three?
But look at me

A person
insecure and apprehensive as doctors whirl by.
A person.
With thoughts and feelings ... a heart.

What do you see when you’re looking at me?
Simply the girl in bed three?

But I am a person who longs to rollerskate,
dance and skip ... to be well again.

So as I lie here, calm and still,
as I do as you wish,
as I eat at your will.

study me closely as you’re rushed off your feet.
You’re busy on night shift, no time for a seat.
An unusual case, a case to confirm.
No, I’m one of many,
if only you’d learn.

So open your eyes, doctor,
open and see,
not a fascinating case.

Look more closely,
Try to see me.

A. B., aged 11 years

Introduction

In America today we often relegate issues of illness, disease, and death to the world of the elderly. The reluctant admission that death can touch our lives at any age brings us face to face with our own mortality, and serves to remind us that even our children are not immune to suffering and death. Each year in the United States, over 40,000 children under the age of 15 die (Centers for Disease Control and Prevention, 2001). Many of those children live for some time with chronic and life-threatening illnesses such as diabetes, heart disease, organ failure, AIDS, and cancer. Each child is not only influenced by the obvious physiological factors, but also by the financial burden and general disruption of family life created by the illness and its treatment (Hobbes, Perrin & Ireys, 1985). Although the number of children diagnosed with each individual serious and chronic illness is small, collectively these children number well over a million in the United States alone (Hobbes et. al, 1985). When we pause to consider the effects of long-term and life-threatening illness in the families of these children, and in their neighborhoods, schools and communities, we begin to understand the ramifications for our society as a whole. Tremendous support is required to enable families and communities to meet the needs of these children.

In the not so distant past the diagnosis of many serious childhood illnesses meant certain early death. Many children with these same diagnoses are living well into adolescence and adulthood today. As recently as the 1970s, a child given a diagnosis of leukemia, for example, would not have been expected to live beyond several months. Thanks to dramatic developments in radiation and chemical therapies, 90-95% of children with leukemia now achieve some remission and 50% remain in remission for at least five years (Pendergrass, Chard & Hartmann, 1985). It is estimated that one in every 900
adults between 16 and 34 years of age is now a survivor of some form of childhood cancer (Nessim & Katz, 2000).

The progress brought about by medical research and technological advances has brought with it a new set of questions for these young patients and the society struggling to meet their needs. Not only must we tend to the immediate physiological needs of treating illness and minimizing suffering, but we must increasingly look to how to help these children live with illness for months and even years. As Varni and Katz (1987) noted, this development requires an equally dramatic shift in treatment stance beyond immediate crisis intervention, and toward developing a long-term relationship focused on facilitating the child’s coping and continuing adjustment to living with chronic and life-threatening illness.

This is an area in which psychologists in particular contribute greatly to easing the suffering of these young patients and their families. In order to do so, we must open ourselves to learn from their experiences of illness in hopes of understanding where we can meet and support them along the way. How do these children understand illness and its treatment? How do they cope with illness on a daily basis? What emotional and relational issues do they face? How do these children make sense of their illness experiences and incorporate them into their developing life story? In short, what does it mean to the child to live with a life-threatening illness? We must seek to learn from their experience what we, the grown-ups in their lives -- medical staff, psychologists, families and friends -- can do to help.

The scores of individual childhood illnesses, their treatments and courses vary tremendously. This study focused on children diagnosed with cancer, the leading disease killer in childhood. Within the realm of childhood cancers there are, of course, differences
in symptoms, treatment, and prognosis. Indeed, I found similarities as well as important
differences in the way the children who participated in my research live with cancer.

However, taking up a categorical approach of studying the experiences of children within
one category of illness provided a common context from within which to study children’s
experiences of living with cancer. In order to further contextualize the current study, I
will begin with a brief discussion of childhood cancer and its treatment.

Childhood Cancer

In the United States alone approximately 12,000 new cases of cancer are
diagnosed in children under the age of 17 each year (Nessim & Katz, 2000). Granowetter
(1994) has noted that the chances of developing cancer before the age of 15 are 1 in 600.
Cancer itself is actually a group of diseases that are characterized by an “uncontrolled and
unrestrained proliferation of cells” (van Veldhuizen & Last, 1991, p. 1). These quickly
dividing cells are found in the blood in leukemias or as solid tumors that can spread
throughout the organs, bone, and tissues of the body. As has been previously mentioned,
until the early to mid 1970s, childhood cancer in its many forms was almost always fatal.
Untreated, cancer remains a terminal illness. However, thanks to advances in early
detection and treatment intervention, childhood cancer is no longer considered to be an
acute and immanently fatal illness, but is now classified as a serious, chronic life-

The specific course and duration of recommended treatment depends upon many
factors including the stage of the disease at time of diagnosis and, in the case of relapse,
the effectiveness of previous treatments (van Veldhuizen & Last, 1991). Treatments for
cancer include surgery to remove tumors and affected tissue, chemotherapy and radiation
therapy, and bone marrow transplant. Each of these lifesaving treatments also brings
unwanted challenges to children and their families. Surgery leaves children with obvious physical scars, and may also leave them to adjust both physically and emotionally to disfigurement or an amputated limb. Chemotherapy drugs attack not only rapidly dividing cancer cells, but also the body’s normal rapidly dividing cells in the gastrointestinal tract, bone marrow, hair follicles and reproductive system. Chemotherapy often results in negative side effects including nausea and vomiting, loss of appetite, mouth sores, abdominal cramps and diarrhea, joint pain, fatigue, a reduction in blood cell production, fever, hair loss, headaches, liver and kidney damage, damage to the heart muscle and loss of pulmonary function. Radiation therapies may also produce side effects including burns, permanently reduced bone growth and neurological damage. Both chemotherapies and radiation therapies also paradoxically increase the child’s chances of developing a second tumor or leukemia. Hospitalization isolates children by removing them from the security of home, family and friends as well as from regular daily activities (e.g., going to school, riding a bike, playing with friends). The child receiving a bone marrow transplant, for example, may be hospitalized in varying states of isolation for four to six weeks. All of these treatments serve to slow down the once fatal course of cancer. The longer a child remains in remission, the better the odds of remaining symptom-free, but the possibility of relapse or recurrence can never be ruled out. Particularly during periods of remission, the symptoms of cancer may not be constant, but as van Veldhuizen and Last (1991) noted, living for long periods with the chronic uncertainty of a potentially fatal illness imposes a “permanent threat” that looms over the daily life of these children and their families (p. 8).

Children who are diagnosed with cancer face change in virtually every area of their lives. They face physical change which may be temporary, such as hair loss and weight
loss or gain, or permanent, such as disfigurement or amputation. As Levine and Hersh (1982) suggested, these changes serve as a constant bodily reminder of their illness and the uncertainty of their future. They experience change in relationships with parents, siblings and peers, and must often endure repeated separations and shifts in family and peer group dynamics. Children and their families must adapt their time and financial resources to the treatment of the illness. Families must often travel to larger cities for treatment, be that for regular chemotherapy or radiation therapy, or for extended hospital stays and surgeries. Even for those with the best of insurance coverage, treatment is an economic strain on the family. Money may be diverted from long-term retirement or college savings as well as from short term expenditures such as school clothes and supplies, family trips, and activities such as a sibling’s piano lessons or little league equipment. This diversion of time and energy from regular activities and relationships to the care and treatment of the child with cancer has been the subject of much research on the stresses upon parents and siblings of children with cancer (Bluebond-Langner, 1995; Hobbes, et al., 1985; Varni, et al., 1996). The family’s ability to cope with these stresses can greatly affect a child’s ability to cope with ongoing stress. For example, parents who are overly anxious may communicate their anxiety and fear to their children (Melamed & Ridley-Johnson, 1988, cited in Melamed, 1998). Parents who have support in successfully coping with their own anxiety may not relay additional anxiety to their children and may thereby provide a more open environment within which the child’s anxiety may be held and navigated.
Literature Review

I will now review the literature in four primary areas with respect to children living with life-threatening illness. Given that so many of the concepts in studies of children’s illness concepts are based on Piaget’s theory of cognitive development, this review begins with a summary and critique of that theory. I continue by reviewing studies that have sought to understand both well and ill children’s conceptions of illness, treatment, and death, and then consider research on coping models that seek to explain children’s responses to the stress of illness and its treatment. Finally, I will contrast and compare Erik Erikson’s psychosocial theory of development with literature which focuses on known treatment issues for children with cancer who are referred for psychological or psychiatric intervention, including factors that may affect children’s resilience or vulnerability.

Review of Piaget

Jean Piaget’s theory of cognitive development tracked shifts in developing cognitive processes from infancy through adulthood. Through naturalistic observation and questioning of children, Piaget sought to determine the ways in which children’s thought differs from that of adults. Piaget (1972) asked questions that were answered incorrectly by younger children and correctly by adolescents (whom Piaget deemed to have mastered adult thought). Piaget (1972) compared responses given by children of different ages and argued that “whatever [their] answer may be, the meaning behind the words is what matters (p. 38).” In other words, it was not so much what the child said, but the style of his or her response that indicated to Piaget a particular level of cognitive development. Piaget looked to what children’s answers revealed about the limitations of their thought processes. Thus the progression of answers through childhood towards an
appropriately “adult” response was the ground for Piaget’s description of the progression of cognitive development. Piaget described this progression in the development of children’s thought processes as based first on sensorimotor encounters with the environment in infancy, which become less and less dependent on immediate and concrete experiences as the adolescent, and later the adult adopt more logical and abstract modes of reasoning.

Piaget described what he determined to be a predictable series of four stages in the progression of the child’s cognitive development. In the first stage, the sensorimotor period, which is said to span from birth to approximately age two, children are limited in their ability to know the world around them by their still emerging sensory and motor capabilities. Language acquisition and the ability to form basic concepts build upon the experiences and knowledge gained in this first stage and emerge through the following three stages.

In Piaget’s second stage, the pre-operational phase of cognitive development, the thought processes of the child between the ages of two and seven are characterized by egocentric thought. At this level, children’s ability to conceptualize the world around them is limited by their own perspective and immediate personal experiences. Piaget described these children as confused and constrained by their inability to conceive of another external point of view and thereby attend to only one perspective, aspect or dimension of an object or experience at a time. In Piaget’s classic conservation experiments, for example, it is in attending to the “height” of equal amounts of water poured into a tall slender glass and a short stout glass that prompts the child to say that there is “obviously” more water in the tall glass where the height of the water level appears higher. At this stage Piaget described children as confused about causal
relationships in the world, following instead a logic all their own. Children at this stage are said to hold magical notions of cause and effect. Children believe that they can cause actions and events in the world by merely thinking or wishing them to be so.

In the concrete operational stage, spanning from approximately seven to twelve years of age (the age range of the children in this study), the child is involved in decentration, the process of moving beyond the egocentric view to being able to consider multiple perspectives and aspects of objects and events in the world. Here children begin to abandon magical thinking in favor of more logical thinking including more scientifically based ideas about cause and effect. They are capable of describing logical operations and concepts in “broad strokes” even if they cannot yet fill in all the details. These children are involved in ordering and classifying objects in several dimensions, and can understand basic mathematical concepts. However, Piaget maintained that these burgeoning abilities are still dependent upon applying these operations to concrete objects or experiences in the child’s world.

Finally, in the formal operational stage of cognitive development, beginning at twelve years of age or later, the adolescent is able to analyze logical relationships, both concrete and abstract. The individual at this level of cognitive development is able to comprehend and explore abstract scientific and mathematical laws and equations as well as abstract notions of “justice” and “freedom” and has thus, for Piaget, fully adopted adult modes of thought.

Development of Illness Concepts

Studies of children’s illness concepts tend to fall within the broad realm of cognitive-developmental psychology and adhere closely to Piaget’s conceptual framework. These studies have primarily sought to discover the ways in which children
conceptualize health, illness, treatment and death at differing stages in their own cognitive development. These studies have focused on the progression of patterns in the kind of conceptions and misconceptions of health and illness children maintain at each cognitive developmental stage. The vast majority of research in this area suggests that children’s illness concepts develop in a predictable series of stages corresponding to Piaget’s stages of cognitive development.

*Pre-operational concepts.* Researchers in this field contend that children’s illness concepts begin as the rather global, nonspecific and even magical ideas which characterize much of the thought Piaget described in the preoperational child (Bibace & Walsh, 1980; Kister & Patterson, 1980; Band & Weisz, 1990). At this stage, and in comparison to adult conceptions, children’s knowledge of the symptoms and progression of various diseases is described as quite limited. Researchers such as Perrin and Gerrity (1981) found that children at this age gave global and circular responses when questioned about illness causation (e.g., “Why do you think people get sick?” “They just do.”). Preoperational children are also said to overgeneralize that almost any illness, (e.g., tonsillitis, cancer) is contagious and that one can “catch” these illnesses by touching or even by being in the same room with someone who is ill (Eiser, Patterson, & Eiser, 1983; Kister & Patterson, 1980). Children at this age may also “parrot” accurate or inaccurate information about health, illness and death that they have heard from their parents, peers, or the media (Perrin & Gerrity, 1981).

The thought processes of children at this stage are often described as following the moralistic idea that “you get what you deserve." Thus, children who become injured or ill (as well as their young peers) may believe that it happened to them because they were bad. This mode of thinking in the young child has been dubbed *immanent justice*: the
child performs some transgression and is swiftly punished. Sourkes (1995) explained that the concrete thinking of the child “does not easily permit the [adult] concept of randomness to have any meaning. Thus when the illness strikes, [the child] assumes that such things could only happen to someone who is bad” (p. 42). The concept of *immanent justice* had its genesis in the psychoanalytic theory that the anxious patient sees sickness, pain and death (all outcroppings of the original castration anxiety) as punishment for their actions or desires. Anna Freud (1952/1977) wrote that for a child who is ill or injured, “the actual experience [of an operation] lends a feeling of reality to the repressed fantasies, thereby multiplying the anxieties connected with them” (p.7). Taken from quite another perspective, these seemingly bizarre and magical connections that children make between their behavior and their health or illness seem altogether plausible in light of everyday conversations in which children are told by adults, “eat your broccoli so you can grow big and strong,” “you’ll catch your death if you go out without your coat in this weather!” or, “I told you you would get hurt if you played on that jungle-gym.” Perhaps at this younger age children are simply more likely to believe what they are told, even if taken to the literal extreme.

Not only may young children blame themselves for their illness, they may also come to view their treatment as punishment (Lansdown, 1996). This can leave children feeling that they are innately “bad” or, on the contrary, feeling bitter if they believe that they have done nothing to deserve such severe punishment. Sourkes (1995) described such magical thinking and notions of *immanent justice* in a four-year-old patient’s response to treatment: “Whenever [she] came into the clinic, she would chant beseechingly, ‘I’m a good girl, I’m a good girl,’ as if her words could ward off the painful procedures” (p. 42). Many authors have explored the need to dispel this type of
misconception in order to limit children’s noncompliance with often lifesaving treatment regimens that they feel are undeserved or unjust.

The cognitive developmental literature describes a similarly limited understanding of death exhibited by children in the pre-operational stage of development. A four- or five-year-old, for example, may understand (and fear) death as a separation from loved ones, but may not yet comprehend that the separation is permanent or that the dead no longer carry on everyday functions such as eating or walking (Lansdown & Benjamin, 1985, Kübler-Ross, 1983; Nagy, 1948/1995). Death may also be viewed by the child at this stage as punishment (immanent justice) for being bad (Nagy, 1948/1995). The corollary to this is the belief that “if I’m good” the child can escape pain and death. Here children have not yet begun to internalize the processes of illness and death, rather death is understood as something external – even personified as a Grim Reaper character who comes to take bad little children away (Kübler-Ross, 1983; Nagy, 1948/1995).

Concrete operational concepts. As children move towards adolescence, their illness concepts gradually come to be based more on logical cause-and-effect structures and scientific fact (Kister & Patterson, 1980; Nagy, 1948/1995; Perrin & Gerrity, 1981; Bibace & Walsh, 1980; Band & Weisz, 1990). Here the child develops a rudimentary understanding of the physiological processes within the body that they draw upon to explain “getting sick.” At this stage children describe a more scientifically accurate understanding of contagion (Kister & Patterson, 1980). The child at this stage is involved in a process of internalization whereby the child recognizes causal agents (such as germs) which are internalized in the body during periods of illness (Bibace & Walsh, 1980; Perrin & Gerrity, 1981). Nagy’s (cited in Burbach & Peterson, 1986) descriptions of children in the concrete operational stage of development indicated that they have adopted more
adult-like (i.e., scientific) explanations, no longer believing illness to be caused by misdeeds but rather by germs, though they may still overgeneralize this point to believe that all illnesses are caused by one type of germ.

In the face of the extreme physical and psychological stress of being given a life-threatening diagnosis some authors point to the possibility that the child may regress to earlier modes of understanding and coping (Garbarino & Stott, 1989, p. 289). However, most researchers agree that older children who have achieved this “higher order” of concrete operational thinking understand that “immanent justice is a poor reason for illness” (Kister & Patterson, 1980, p. 48). Some more recent studies have shown that school-aged (and even younger) children do not necessarily use self-blaming immanent justice explanations of illness (Perrin & Gerrity, 1981). Lansdown (1996) suggested that there may be a shift across age and developmental levels away from immanent justice explanations for illness due to increased care taken by adults today to explain illness diagnoses and prognoses to children (p. 48).

In both medicine and psychology the concept of “coping well” or hopefulness on the part of ill children is interpreted by some an indication that they simply did not know, did not understand, or were in denial of their diagnosis and prognosis (Cotton & Range, 1990; Koocher & O’Malley, 1981). This suggests that if the children understood the nature of their illness – if they recognized that they might not get better – then they certainly would not be hopeful or coping so well. Commenting on the paucity of research prior to the 1970s, Lonetto (1980) speculated that reluctance to study children with life-threatening illnesses may have resulted from the widespread belief that terminally ill children did not have the intellectual ability to understand the significance and life-threatening nature of their diagnosis (p. 172). However, as Spinetta argued as early as
1974,

... the fatally ill six- to ten-year old child is concerned about his illness and that even though this concern may not always take the form of overt expressions about his impending death, the more subtle fears and anxieties are nonetheless real, painful, and very much related to the seriousness of the illness that the child is experiencing. Whether or not one wishes to call this anxiety of the child about his own fatal illness, though not conceptualized, death anxiety, seems to be a problem of semantics rather than of fact (as cited in Lonetto, 1980, p. 176-7).

It would appear that children at this age and even earlier have and live their own understanding of death whether or not it accurately reflects our adult conception. Most researchers today agree that by at least the age of eight or nine children of normal intelligence, healthy or ill, have begun to understand key subconcepts of death including its permanence (or irreversibility) and universality (Lansdown, 1990; Kübler-Ross, 1983). Lansdown and Benjamin (1985) interviewed children between the ages of five and nine about their understanding of death and the subconcepts involved in a mature conception of death (i.e., irreversibility, universality, causality). This study scored healthy children’s “death comprehension” by age, finding that between the ages of five and seven children correctly scored between 59 and 73 percent of questions, whereas children between the ages of eight and nine correctly scored 96 to 100 percent (Lansdown & Benjamin, 1985). These studies were later repeated using leukemia patients whose overall scores by age were similar to those of healthy children (Clunies-Ross & Lansdown, 1988).

Formal operational concepts. In the final stage of cognitive development, formal operations, illness concepts embrace adult scientifically based and detailed understandings of underlying physiological processes. At this age and beyond, there is an understanding of the complex interaction of illness and bodily variables including the effect of psychological factors (such as being “stressed”) on health and illness (Brewster, 1982;
Perrin & Gerrity, 1981). Research by Band and Weisz (1990) supported the idea that adolescents can understand information about their disease, its prognosis and treatment, that they can and should participate in informed decisions about their treatment, and that having this information significantly and positively effects their adjustment. In this highest level of cognitive reasoning, the adolescent is understood to have a fully mature (i.e., scientific) conception of death.

Effects of experience on illness concepts. Most cognitive developmental research maintains that the development of illness and death concepts seems to follow this same progression in both healthy and ill children (Brewster, 1982; Lansdown, 1996, Perrin & Gerrity, 1981). There is debate in the literature, however, as to whether children who have had hospital and illness experiences are following this progression at an advanced or delayed rate in comparison with their well peers. Early research found that hospitalized children had not only less mature conceptions of illness, but also tested as less cognitively mature in general compared to their well peers (Cook, 1975 cited in Burbach and Peterson, 1986). Burbach and Peterson (1986) speculated that children who were confined to hospital repeatedly or on a long-term basis might simply have had fewer real-world interactions and experiences upon which to develop what are considered to be more advanced cognitive concepts (p. 319). The children involved in these earlier studies were also, however, subject to what was known as the “protective approach” wherein it was assumed that children were simply unable to understand, process or cope with information regarding diagnosis, prognosis and death (van Dongen-Melman & Sanders-Woudstra, 1986, 146). Given this perception, children were simply “protected” by not having this information shared with them. In this case, the information given them (e.g., “It’s not serious,” “You’re not that sick,” “You’re going to get better.”) may well have
contradicted their own experiences leading to confused concepts about the nature of illness and death. Contrary to this early trend, Brewster’s 1982 study of hospitalized and chronically ill children found that ill children tested at *equal* levels of cognitive and illness concept maturity as their well peers. Others have since compared the health and illness concepts of ill and well children and concluded that children with hospital and illness experience have *more* sophisticated illness concepts than their peers (Eiser, 1985; Jay, Green, Johnson, Caldwell, & Nitschke, 1987; Redpath and Rogers, 1984; Reilly, Hasazi, & Bond, 1983). Redpath and Rogers’ (1984) data, for example, suggested that older children in particular may already have more advanced cognitive structures and illness concepts in place that perhaps allow them to better interpret their illness and hospital experiences in such a way as to advance their concepts even further.

Additionally, it may be that children receiving treatment for cancer and other illnesses today receive much more personal and detailed information and explanations of their illness and its prognosis from health professionals, child life specialists and parents, allowing them to develop more advanced concepts than their peers who may lack both the experience and information (Jay et al, 1987). Such variance in results may also speak to methodological differences in the way in which responses are elicited from children and by which the child’s developmental level is assessed.

**Critiques of stage theory.** It is important to note here that not all research nor all researchers within the field agree with this cognitive-developmental model as the basis for understanding children’s developing illness concepts. Eiser (1985; 1989; Eiser, Eiser, Lang, & Mattock, 1990) has repeatedly argued against the cognitive-developmental “stage theory,” demonstrating through her work that children’s personal *experiences* with illness and death serve as a more reliable explanation for their understanding of these concepts.
In her work with ill children, Sourkes (1995) found that children’s past experiences with illness and loss directly impacted their ongoing reactions to their diagnosis and prognosis. The appreciation of the role of experience in the child’s developing illness concepts led researchers such as Bluebond-Langner (1995) and Lansdown (1996) to describe stages of increasing understanding of disease and prognosis, which do not follow the child’s cognitive developmental stage, but rather the chronology of the illness and the experiences that the child encounters along the way. Through her research with terminally ill leukemic children, Bluebond-Langner (1995) found that in order for children to pass through these stages, significant experiences and events must take place (p. 237). These catalytic experiences include the child observing the reaction of parents and others to his or her diagnosis, experiencing relapses and remissions, and the death of a peer. In this model, terminally ill children progress from understanding that they have a serious illness, learning the terminology of their illness including the side effects and purpose of treatment, learning that they have an illness that kills children like themselves, and finally, in terminal cases, coming to fully understand and internalize their prognosis – that they are terminally ill and will die (Bluebond-Langner, 1995).

Beyond the critique that Piagetian theories fail to adequately take into account the experiences of individual children, there remain questions as to the fundamental biases of such theories of cognitive development. Sipiora (1993) has argued that though Piaget begins with observation and questions derived from children themselves, he fails to value the child’s experiences and responses on their own terms but rather leaps to interpretations which reduce the child’s experience to an immature, confused and deficient mode of adult thought. Piaget (1972) himself stated that, “the explanations a child gives in answer to one of our questions must not be taken as an example of ‘a child’s ideas’, but
serves simply to show that the child did not seek the solution in the same direction we should have” (p. 123). Piaget thus attended more to the negative findings of what is lacking in the child’s thought and less to the positive of what is present and experienced as meaningfully revealed through the child’s responses. Sipiora (1993) continued that such movement away from the explanations directly offered by children to interpreting these explanations as deficient modes of adult thought, “results in the repression of an authentic disclosure of the life-world” (169). In this light, Piaget’s research never ultimately answers the question of how the child experiences the world of health or of illness.

The literature on children’s developing conceptions of illness has been valuable to health professionals seeking to improve communication with young patients. Such information has been used to help identify patients’ understanding of illness and treatment thus allowing professionals to provide children with information in a language that they can understand.

While some researchers have begun to look to the role of ongoing experience in shaping the child’s cognitive conceptualization of illness, treatment and death, little has been made of the reciprocal turn to understanding what these conceptualizations reflect and reveal about the child’s ongoing experience of illness. How does their cognitive understanding come to bear on how children live and make sense of life with that illness? How do children’s own narratives shift with the changes they experience and with their unfolding understanding of illness and death? In short, how does this cognitive piece fit into the larger issue of the child’s experience of illness?

**Coping**

Any single aspect of the child’s experience of cancer could be considered
traumatic. Being given a diagnosis of a potentially fatal illness; being isolated from friends and family while in the hospital; undergoing frequent painful medical treatments and procedures; suffering bodily mutilation – any of these would certainly be traumatic on its own. But the child with cancer must endure a whole sequence of traumatic events, often repeatedly. Much research in the area of childhood cancer has been devoted to how children respond and adjust to the traumatic events that may unfold on a daily basis when living with this life-threatening illness.

*Development of coping models.* Early models of coping were based on behavioral and physiological research often drawing on studies of animal behavior. Coping behaviors observed in the laboratory were explained as reflexive escape or avoidance behaviors evoked in response to noxious stimuli (Lazarus & Folkman, 1984). Much of today’s research is based upon cognitive-behavioral models developed through research on adult coping processes. These models emphasize the interaction between idiosyncratic and enduring attributes of the individual and the individual’s ability to change, adapt, and grow in response to specific situational factors. Here, the understanding of coping has evolved beyond a merely reflexive “fight or flight” response to understanding action as rooted in the individual’s appraisal of the situation and determination of the best available response (Parle & Maguire, 1995). Although this model takes into account the individual’s interaction as more than reflexive, it may incline us towards a view of coping as a detached and rational decision-making process.

Two specific models of adult coping behavior became the foundation for much of the current research on coping in children: (a) the *two-process* model developed by Rothbaum, Weisz and Snyder (1982), and (b) the *ways of coping* model developed by Lazarus and Folkman (1984). Rothbaum, et al. (1982), identified global categories of
primary control strategies aimed at influencing objective (external) stressful conditions, and secondary control strategies aimed at influencing the psychological impact of those conditions. Similarly, Lazarus and Folkman (1984) described specific categories of problem-focused coping which involve ways of trying to manage or modify a stressful situation or event and emotion-focused coping which involves managing and reducing the emotional distress which accompanies stressful situations and events. Similar groupings of coping strategies have been labeled by other researchers as active and avoidant strategies, or as behavioral and cognitive techniques (Spirito, Stark & Tyc, 1994).

Models of coping that have been applied to children flow from this work with adults. Research involving ill and hospitalized children tends to adopt the same categorizations, grouping coping responses into two broad categories, those that describe children’s efforts to cope with “external” conditions such as receiving a bone marrow aspiration; and those that describe children’s efforts to cope with their “internal” or psychological response to these conditions, such as feeling anxiety in the face of a medical procedure. Band and Weisz (1988) identified primary or problem-focused methods used by children in response to everyday stress including: (a) direct problem solving; problem-focused coping which seeks to elicit assistance from others; (b) problem-focused aggression; and (c) problem-focused avoidance including efforts to directly avoid experiencing stressful events. Children may utilize an emotion-focused or secondary control approach by (a) eliciting social or spiritual support; (b) emotion-focused crying, which serves to elicit comfort (rather than direct assistance) from others and to release “pent-up” emotions; (c) emotion-focused aggression, involving a physical or verbal attempt at emotional release; (d) cognitive avoidance in which the child seeks distraction from thinking about stressful circumstances; and (e) pure cognition in which the child
reduces emotional distress through fantasy or a shift in thinking about the situation (Band & Weisz, 1988). Band and Weisz (1988) identified a less frequently occurring pattern in children of relinquished control in which the child neither attempts to actively change circumstances as they are nor to adjust to them, in essence resigning or “giving up.” Each of these categories was developed through an analysis of children’s responses to hypothetical stressful situations. Under actual conditions of stress and trauma other factors, such as the physical weakness experienced by children undergoing chemotherapy, may intervene and help shape the choices these children perceive to be valid responses to their situation.

These models used to describe the experiences of both adults and children take as their ground a split between coping responses that are aimed at managing internal or external stressors. It is important to note that the attempts by researchers to order and clarify experiences may serve to artificially split and simplify an experience that is lived as more unified and complex. Often our experience and response is more “messy,” requiring us to respond to multiple challenges or “stressors” on multiple levels. This method of categorization may better serve as a useful means of organizing and coding research data than as a faithful description of the experience of making sense of and living through a traumatic event such as cancer.

Children’s coping strategies. To date, much of the research that does take into account the child’s experience through self-report does so by utilizing checklists or standardized questionnaires with Likert-type scales (often appearing for children as a progression of faces from happy to sad) used to identify specific stressors, rate how often children engage in particular coping strategies, how many of these techniques they employ, and how effective children (or others) perceive their responses to have been.
These studies tend to explore coping responses to specific stressors and events, rather than to the global stressor of “having cancer.” Some of the specific demands of cancer upon these young patients (e.g., side effects of chemotherapy, school absences, strain on the family) have already been mentioned, but which of these or other specific stressors are of most concern for the child with a chronic and life-threatening illness such as cancer? In a study of stressors faced by hospitalized children, Spirito, et al. (1994) asked children to describe “a situation that has bothered you since you have been in the hospital.” This questioning led to descriptions by the children of concrete stressors or “pet peeves” including: hospital-related stressors (e.g., noise, bad food, getting woken up throughout the night to have vital signs taken); pain-related stressors (e.g., pain of needle sticks or removing IV tape); and illness-related stressors (e.g., difficulty breathing, nausea and weakness following chemotherapy, fear of dying).

Utilizing a strikingly different approach, Spitzer (1992) engaged young hemophiliac patients in telling stories about illness which were then linked to the child’s own experiences and meaning. This different approach, grounded in the stories, language and experiences of the child, reveals different concerns. She found that they described demands upon them that could be clustered into three major areas of concern: existential concerns (e.g., “What will happen to me?” “Am I going to die?”), treatment concerns (“Will I have to have blood drawn?”) and concerns about being “different” (Spitzer, 1992).

Within this framework it is now generally accepted that coping strategies vary as a function of a child’s (chronological and developmental) age, experience, and the context of the immediate crisis or stressor. Responses typically observed in younger children tend to include secondary or emotion-focused responses such as distraction, self-soothing, and
crying (Mellins, Gatz & Baker, 1996). These early responses to stress are generally viewed as “less mature” and regressive when they are used as the primary mode of coping by older children. In young (pre-formal) children, the amount of control they perceive that they have over their illness, treatment, and other everyday events and decisions has been positively correlated with adjustment to their medical conditions (Band & Weisz, 1990). Older children, adolescents and adults tend to employ other techniques such as behavior controls and information seeking (i.e., attempting to learn as much as possible about one’s illness and treatment options) (Band & Weisz, 1990; Mellins et al, 1996; Spirito et al, 1994). Just as modes of emotional regulation may be viewed as regressive or less effective modes of coping for older children, information seeking, for example, has been shown to aid in adjustment for older but not younger children (Band & Weisz, 1990). It is assumed that the younger child does not have the cognitive structures in place to grasp a full and detailed explanation of illness and treatment in the way that the older child can.

*Children coping with cancer.* Worchel, Copeland and Barker (1987) identified four types of coping strategies based on the traditional premise of control which were employed by pediatric oncology patients in attempt to exert control over some area of their illness and treatment: informational, cognitive, decisional, and behavioral. Informational control was observed in children’s asking questions in an attempt to gather information about their cancer and its treatment. Cognitive control occurs when children think about and talk about their illness. Decisional control is witnessed in children’s decision making (or perceived ability to make decisions) regarding daily activities (e.g., what to eat or whether to go to school in the morning) and medical treatments (e.g., deciding when to have a treatment). In this study, behavioral control strategies were
positively correlated with measures of emotional adjustment and served to be the best of the four modes for predicting a child’s level of emotional adjustment (Worchel et al., 1987). Finally, behavioral strategies may include the use of relaxation, guided imagery and hypnosis techniques to control or reduce the discomfort of medical procedures, treatment side effects, or general anxiety felt by the child with cancer.

Kugelmann's (1992) description of the “rhetoric of control” can be seen operating throughout these models. Children are seen to suffer at the loss of control they experience during illness, and so alternate means of recapturing behavioral and emotional control are suggested (Band & Weisz, 1990; Worchel et. al., 1987). We must question if feeling mastery over a situation should constitute healthy adaptation – particularly in the face of a life-threatening illness where life and death are indeed beyond one’s immediate control. If a child comes to feel a sense of mastery (real or illusory) will he or she be “unfazed” by the circumstances? By promoting the value of control, including the military metaphor of keeping up the “fight,” do we set up children to feel betrayed or guilty when circumstances out of their control face them with relapse, continued sickness, or death? How then is the child to assert their control? Perhaps another metaphor or way of framing the experience would not preclude responses that are not directly goal or mastery oriented.

Categorical and contextual considerations for coping. Band and Weisz (1990) found that children with juvenile diabetes who used primary coping strategies (i.e., aimed at influencing external conditions) scored higher on measures of medical and sociobehavioral adjustment than those who used secondary coping strategies (i.e., aimed at influencing the psychological impact of their situation). It is notable, however, that children with juvenile diabetes are actively involved in exercising and monitoring an
improved diet. These behaviors, though clearly injunctions upon which the child’s health and even life rest, allow the child to directly impact the course of their illness, its severity, and the need for further and more invasive treatment as well as on their overall quality (and quantity) of life. This active involvement is critical to maintaining health. No such active participation can be offered to children with cancer; there are no such behaviors available which could directly affect their prognosis. They may have a choice of receiving or refusing surgery or chemotherapy treatment, but this life or death decision is usually made for them by their physicians and parents.

In her research, Spitzer (1992) discovered that the types of coping responses observed in and reported by school-aged hemophiliac children depended upon the context in which the specific responses occurred. For example, in aspects of their illness where children perceived that they had some control, they tended to engage in predominantly problem solving (primary) coping, such as avoiding rough play that could result in a cut or bruise or immediately applying pressure to stop a bleed. However, in those areas over which they believed they had little control, such as in being hemophilic or needing to have blood drawn at a doctor’s visit, children predominantly used emotional regulatory (secondary) modes of coping. Similarly, children with cancer may by necessity engage in more secondary or emotion focused measures of coping to do what they can to minimize or adjust to the psychological distress they feel in response to their illness. It is clear that from a noncategorical approach (i.e., comparing the coping of children with cancer to children with juvenile diabetes or hemophilia), children with cancer may be judged to engage in “less effective” or passive coping behaviors. However, a closer (categorical) look may reveal that the selection of these coping responses makes sense within the context of a diagnosis and prognosis over which the child has very little control. In fact,
Van Veldhuizen and Last (1991) observed that young cancer patients and their families who “usually have very few possibilities to change the actual situation and to exercise direct influence on the course of the illness ... are forced to appraise [italics added] the situation in such a way that it will be understandable, acceptable, and endurable for them (p. 1).” Such findings point to the child’s attempts to make sense of what it means to live with illness – to re-story their experience to incorporate these new and painful experiences. These observations seem to highlight the need for further categorical studies of the experience and context of coping in children who are living with cancer.

**Defining “coping.”** Much debate in current literature centers on whether to define coping as what a person does to adapt to a stressful event or circumstances, or rather how well the individual has succeeded in adapting (Parle & Maguire, 1995). Many traditional quantitative studies have defined coping as the observable behaviors performed in response to stress. In fact, many studies involving young cancer patients and other ill and hospitalized children rely heavily on reports from their medical staff and parents who describe the patient’s coping behaviors or serve to corroborate or refute the child’s self report (Morrissey, 1963 (cited in Lonetto, 1980); Varni, et al., 1996; Worchel, et al., 1987). This approach has proven useful particularly in identifying concrete behaviors such as hand-holding during a painful procedure that the child may not recognize or think to report as a helpful coping strategy, as well as in identifying potential discrepancies between the child’s reported coping strategies and those observed by parents and staff. Such an approach is, however, limited in its reliance on other’s observations and interpretations of the child’s coping rather than on the experience of the child. This approach may also prove problematic depending upon whose standards and values (i.e., parents, medical staff, psychologists, or the child) form the basis for evaluating whether
the child has successfully adapted or coped with the demands of the illness. In reviewing the literature on children’s coping with diabetes, for example, Band and Weisz (1990) found that coping is frequently viewed as compliance with the medical regimen. Would we then be correct to assume that the children who are coping the “best” are those who follow the demands of their medical regimen without showing or giving voice to anxiety or depression? These children may be experiencing anxiety or depression as well as coping in ways that we may fail to observe. Much of the richness, complexity and certainly the meaning of the experience to the child is obscured by this approach to the phenomenon.

In attempt to understand children’s perspective on their own coping behaviors, some studies have begun to turn to self-report, asking children to describe the perceived efficacy of their coping techniques (Band & Weisz, 1990; King, et al., 1990). These researchers, however, tend to quantify children’s experience, asking, for example, “How are you coping on a scale of one to five?” These studies offer statistical data on, for example, how many children report feeling “really bad” most of the time or who feel that their coping behaviors help “really a lot” or “not much at all.” These studies are, however, dominated by a language pre-established by the researchers and theorists, rather than the language that flows from the experiences of their participants.

Some ambiguity remains in the literature as to the precise definition of “coping.” A recent debate in the American Psychologist centered on whether “coping processes” identified in the literature are or are not distinct from what have traditionally been defined as defense mechanisms (Newman, 2001; Cramer, 2001). Cramer (2001) made a distinction between the defense mechanism which, she argues, is an unconscious process which defends against stress, and the coping strategy as a conscious process to cope with stress. Newman (2001) contended that the two concepts are intertwined and therefore
should not be categorically distinguished, “defense mechanisms are processes used to cope, and coping process are mechanisms that can be used to defend against threatening thoughts and feelings” (p. 760). This identification of coping as a brand of defense mechanism focuses on the negative, or defensive dimension of this process. A more broad understanding of coping might also admit the positive, creative and meaning-making dimensions.

Two leading researchers in the development of coping models, Lazarus and Folkman (1984) defined coping as efforts to manage demands “that are appraised as taxing or exceeding the resources of the person (p. 141).” In tracing the origins and development of stress and coping models, Brown (1999) and Kugelmann (1992) described engineering, administrative and military metaphors implicit in the literature including Lazarus and Folkman’s popular conceptualization. Kugelmann argued that these metaphors carry enticing expectations of “rational, efficient, and successful decisions about how to cope” (p. 30). He continued that the language of, “‘appraisals,’ ‘costs-rewards analysis,’ and ‘evaluation of probable outcomes’ suggest systematic rational analysis, connoting the managerial processes that supposedly reign in the boardroom, and which aim at efficiency and productivity.” In such models the larger and more depthful lived experiences of the child living with cancer, the process of making sense of the traumatic (“stressful”) circumstances into which the child has been thrust, have been reduced in essence to the “cost-rewards analysis” of a detached administrative metaphor.

The vast majority of coping models described above are grounded (explicitly or implicitly) in such metaphors and employ what Kugelmann named a “rhetoric of control”

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1 Across disciplines similar critiques have been leveled against prevalent “rational choice” metaphors in Economic theory which seek to explain complex and over-determined human social behavior in just such terms of detached cost-benefit analysis (Sutton, 2001).
as a solution to the stressors, small and large, that we encounter in our everyday living. Contemporary models of coping speak of *influencing* the impact of external or internal conditions (Rothbaum, et al., 1982). We encounter this again in Lazarus and Folkman’s language of *managing, modifying* and *reducing* stressful events. Kugelmann spoke to the importance of identifying and making explicit such underlying metaphors in stress and coping models. Indeed, as Kugelmann posed, “the rhetorical texture of the discourse ... conveys attitudes about the self and the world” (1992, p. 27). In models which focus on “control” as a solution, Kugelmann argued that we are “enticed” to “accumulate power (energy, boundaries) in order to deal with it” (Kugelmann, 1992, p. 27). Many of the strategies offered by these approaches offer concrete “things to do,” or ways to “control” their stress, such as teaching breathing exercises that help them *manage* the pain of a spinal tap are certainly valuable tools for children and adults. Indeed, Sourkes (1995) noted that patients rate these techniques as very effective. Even when such behavioral coping strategies cannot *objectively* improve symptoms, children report a *subjective* sense of increased self-control (Sourkes, 1995, p.62). Such perceived control and efficacy have been positively correlated with emotional adjustment and may have a potentially positive effect on prognosis (Holland & Lewis, 2000). That said, we must be reminded that these models and their underlying metaphors may *preclude* other modes of “dealing with” issues raised in living with live-threatening illness.

Traditional models of framing the experience of coping as rational analysis or alternately as defense mechanism situate the individual in a posture of defense or mastery in relationship to his or her world. Even within the more traditional mind set, researchers such as Taylor (1983) have begun to describe what adult cancer patient consider to be a “search for meaning” (in addition to attempts to regain mastery and restore self-esteem)
as a central theme to the process of adjustment among cancer patients. This search for
meaning, identified by the breast cancer survivors in Taylor’s research, is often reported
as a “reappraisal” of one’s life – a re-narration of one’s life story which attempts to make
sense of and integrate the experience of illness as meaningful. This and similar accounts
based on individual experiences may point us towards a broader and more depthful
understanding of the meaning of the cancer experience and the ways in which both
children and adults come to adjust to the changing demands of living with cancer.

These methods for research into children’s coping responses have yielded valuable
statistical information regarding the type, frequency and perceived efficacy of specified
coping responses, but they are limited in requiring individuals to identify their experiences
through the researcher’s language and specified categories and in reducing the child’s
ability to describe complex experiences to a quantitative scale.

Psychological and Treatment Concerns

Psychosocial developmental issues. We now turn to the psychosocial issues
which frame the child’s experience. It is important to look to issues which arise in the
treatment of children with cancer and other illnesses who are referred for or seek
therapeutic intervention. However, it seems equally important not to rush to pathologize
all patients. There may be some responses, including some level of anxiety and
depression, that could be expected as a “normal” response to the “abnormal” world of the
child as patient. In order to better understand and situate the issues that become most
poignant or problematic for children who are ill, it may be helpful to view at least some of
these struggles in the light of the ongoing process of psychosocial development
particularly from preschool through adolescence.

Erik Erikson (1950) described the play age, what we now commonly refer to as
the preschool years, as a time in which the child actively explores the world and develops a sense of initiative. The child emerges from this time with a sense of being able to do and accomplish things in the world and with a basic sense of purpose. Most significant relationships for children at this age are still those of the immediate family. Children learn their role and purpose within the relationships of their own family system. Erikson (1985) wrote that the core pathology of this stage involves children who develop a sense of inhibition, feeling a lack of initiative or guilt in their undertakings, such that they lack that basic sense of confidence and purpose.

The child at this age who simultaneously struggles with a chronic or life-threatening illness may find that projects and initiatives in the world are put on hold while the family tends to the treatment of the illness. As we have already discussed, the diagnosis and ongoing treatment of childhood illness usually brings dramatic shifts in the family system (Sourkes, 1995; Varni et al, 1996). Children may be inhibited in their the ordinary exploration and engagement with the world by the weakness and limitations of their own bodies, their relative isolation in the hospital, or by the admonitions of protective parents and medical staff. In this early stage, children who are building upon a new found sense of autonomy, being able to do things for themselves, may find that they are again dependent upon others for their care. In addition, many authors have identified the primary fear of ill and hospitalized young children as fear of separation or abandonment (A. Freud, 1952/1977; Kübler-Ross, 1983; Carter, Urey & Eid, 1992). In response to this fear, young children may regress into even more dependent or “clingy” behaviors.

For Erikson, the school-age was a period charged with issues of industry and inferiority as the child moves out beyond the protective nest of the family to the
neighborhood and school. The child is engaged in learning new skills, physical and academic, all the while conscious of how well these tasks are mastered in relation to peers. The child emerges from this stage with a basic sense of self-competence. Erikson (1985) described the central pathology of this age as inertia – the inability or unwillingness to engage in new tasks and to develop competence.

School-aged children on the whole seem to be less vulnerable than preschoolers to psychological problems associated with illness and hospitalization. Perhaps, as Marshall and Katz (1989) suggested, they have developed the emotional and social resources that allow them to understand and better tolerate both medical treatments and separation from parents (p. 281). At the same time, the child who would normally be engaged in learning new tasks at school and forging new friendships with peers may have to endure repeated absences from both. This may well leave children feeling “left behind” by the material being taught and the friendships being formed in their absence. Some school-aged children suffering from serious illnesses may develop school avoidance as a manifestation of troubling separation issues with parents and their erratic attendance at school (Sourkes, 1995, p. 101). Beginning at even this young age children are keenly aware of “in” and “out” groups among their peers. They may feel left out if they cannot be at school or participate in after-school activities with their friends. School-aged children with life-threatening illnesses like cancer are also keenly aware of how they are different from other children. School-aged peers may tease or reject a child who has lost hair from chemotherapy treatments or who otherwise looks or acts “different.” School experiences of children with cancer may also be effected by an overall decline in IQ, though most children continue to function within the normal range (Eiser, 1981). These patients often experience significant declines in academic performance which may reflect not only
neurological impairment following the disease and its treatment, but also the psychological impact of frequent absences from school and real or imagined rejection by peers in the school environment (Deasy-Spinetta, 1981; Eiser, 1981; van Dongen-Melman & Sanders-Woudstra, 1986).

Finally, Erikson (1950, 1985) described adolescence as the period of identity crisis in which teenagers create and discover who they are in relation to friends, the values of their families of origin, and the ideals they carry into the future. Here, peers become increasingly important as the relationships through which teenagers begin to define themselves. Adolescents emerge with the ego strength of fidelity: the ability to be faithful to “my sense of who I am and who I want to be as well as to my values and ideals,” and in young adulthood, faithful to “my commitment” to another.

Adolescents coping with cancer face the struggle for independence and autonomy made more difficult by the teenager’s continuing dependence upon parents (and other authority figures including medical staff). Adolescents with cancer find themselves longing for independence, yet dependent on these authority figures for basic care and treatment. This struggle is highlighted by the frequent loss of autonomy experienced by children and adolescents with serious and chronic health conditions. It is evident from the number of coping responses researchers have identified as “control strategies,” that this is seen as a frequent treatment issue for children with chronic and life threatening illnesses, including cancer (Band & Weisz, 1988) Children with cancer may suddenly find that important and mundane decisions are made for them including the type and duration of the treatment they must endure, the time and place of those treatments, where they will stay and with whom, what they may or may not eat in the hospital, whether or not they will be able to attend school for a given day or semester, and whether or not they can see
or engage in regular beloved activities with friends. Many researchers and psychologists stress the importance of providing children with some sense of autonomy, whether that be by teaching them behavioral techniques they can use to “control” the pain they feel during procedures, or allowing children to choose (“control”) their own activities – what they will do, how they will do it, and with whom – in a hospital playroom. For adolescents, this autonomy extends to arming them with information about their illness and treatment so that they can be actively involved in treatment decisions (Band & Weisz, 1990; Worchel et al, 1987).

Coping with loss and the possibility of death. Researchers and therapists report that children with cancer encounter change in their perception of themselves as healthy “normal” children to children who are ill and different in appearance and experience from their peers. It would follow that they must create new narratives that will allow them to account for their changing life circumstances as a child living with cancer. For Anna Freud (1952/1977), these changes each reflected loss in the life of the child: loss of energy, loss of relationships and activities, as well as dreaded loss of life. This fear of death represents not only anxious fantasy, but also the reality of a potentially fatal diagnosis. Sourkes (1995) noted that even though today cancer patients often respond well to treatment, the subjective experience of first receiving a diagnosis of cancer still often signifies death to patients and their families. Thus, diagnosis itself may begin a cycle of anticipatory grief reflecting “the anguish of threatened loss” (Sourkes, 1995, p. 35). These children are often reported to suffer heightened levels of anxiety in the face of their uncertain survival (Koocher & O’Malley, 1981; Spinetta & Deasy-Spinetta, 1981). Today the child with cancer may live for years with lingering uncertainty. As we will soon discuss, it has been suggested that this chronic increase in anxiety may make the
child more susceptible to immediate and long-term psychosocial problems (van Dongen-Melman & Sanders-Woudstra, 1986).

*Altered body and self image.* Beyond an imagined fear, children and adolescents with illnesses such as cancer often have to cope with an actual altered body and accompanying altered body image. Winnicott (cited in Davis & Wallbridge, 1981, p. 38) described the body of the child (and later the adult) as the “dwelling place of the self.” This process of personalization begins arguably with the “mirror stage” in which children first comes to recognize themselves (with prompting from parents) in a mirror. This process locates my identification of who I am with my reflection in the mirror – my physical appearance (Merleau-Ponty, 1964; Lacan, 1949/1977). For children who experiences temporary (e.g., hair or weight loss) or permanent (e.g., amputation) change in appearance, the process of adapting to this altered body image requires an alteration in their lived sense of who they are and what they can do with their body in the world, from climbing a tree, to attracting the admiring glances of others. Coping with temporary physical changes may be initially difficult, but as Sourkes (1995) notes, many children come to develop a matter-of-fact and even humorous acceptance of these changes. As an example, I had the opportunity to meet a ten-year-old boy who came to a holiday party straight from a trip to have a CT Scan to check the status of a brain tumor. The technician had to draw orienting marks on the boy’s head to guide the scan. The child came to the party armed with festive green and red markers for everyone to add their own messages and drawings to the marks on his head. In contrast, coping with a permanent loss of function and, as Sourkes noted, the child’s sense of “intactness” may require a more lengthy process of coming to accept this altered body and self image as well as learning what it means to live, move and encounter the world in this “new” body (1995,
She described this process for an eight-year-old child who suffered some disfigurement after the removal of a large tumor in her cheek: “In the first few months after her diagnosis, her affect was flat, and she talked very little. Eventually she told the therapist, ‘I keep looking for myself in the mirror, but I can’t find me’ (Sourkes, 1995, p. 48).”

**Struggling with being “different.”** Finally, As previously mentioned, Spitzer (1992) identified concern about being “different” as an important and difficult issue for school-aged children suffering from hemophilia. Spitzer found that her hemophilic participants struggled with being “different,” and in fact often disassociated themselves with terms such as “different” or “sick,” insisting instead that they were “normal” or at least not as sick as other kids. There is a need for research on cancer and other life-threatening illnesses which would specifically explore children’s struggle with identifying themselves as “patients” and how this self-understanding contributes to their experience of the illness. This and many of the other dimensions of living with cancer we have discussed require an alteration in the child’s narrative about what it means to be a child living with cancer.

**Increased risk for disorder.** It has been reported that over one third of hospitalized children (including those hospitalized for injury as well as illness) are diagnosed with either short- or long-term psychological reactions including excessive fears, regressive behavior, anger and aggressive behaviors, and social withdrawal (King, Gullone & Ollendick, 1990; Melamed, 1998). Researchers have also identified childhood cancer survivors as being at a higher risk for developing emotional disturbances than survivors of other chronic but non-life-threatening illnesses (Katz, Kellerman & Siegel, 1980; Koocher & O’Malley, 1981). Increased symptoms of anxiety, depression, anger,
withdrawal, insomnia, and nightmares have been reported in children with cancer (Katz, et al., 1980). Research tends to support the hypothesis that children with cancer do indeed demonstrate elevated depressive symptoms (Katz, et al., 1980; Bennett, 1993). Children who have difficulty coping initially may develop increased anxiety in the face of repeated procedures, treatments and other accompanying stressors (Melamed, 1998). In addition, children may develop conditioned anxiety associated with treatment (Kellerman & Varni, 1982). Here, for example, you may find a child who habitually begins to feel nauseous or who vomits upon entering the parking garage of the hospital on the way to receiving chemotherapy treatment. While children with cancer may undoubtedly experience symptoms of depression and anxiety, it is important to note that these children may not demonstrate clinically significant variance in these symptoms and that they do not necessarily show more depressive or anxious symptoms than their healthy peers (Phipps & Srivastava, 1997).

Risk and Resilience

The stress of living with cancer is unquestionable, but each child’s vulnerability or resilience to that stress is influenced by many different factors. Not all children who are hospitalized or who are treated for cancer go on to develop affective disorders or become otherwise profoundly negatively influenced by their experiences (Bolig & Weedle, 1988). Indeed, there is a danger in generalizing issues faced by children who have developed clinical issues and who have been referred for treatment and assuming them to be the experience of all children with cancer.

Garmezy and Rutter (1983) studied “stress-resistant” or resilient children and discovered factors that seem to protect children from suffering overly negative consequences of negative events and experiences. These include personality traits such as
self-esteem, a cohesive family, and a support system (within or outside of the family) which encourages the child in communicating and coping with the illness and its treatment. “Protective factors” have been identified which seem to similarly predict the likelihood of successful long-term adjustment to cancer and other chronic life threatening illnesses. These include early age at disease onset, early knowledge of diagnosis, supportive and communicative family and support system, short treatment course, and no or low reoccurrence of the illness (Mellins, et al., 1996). The severity of the illness plays a key role in the child’s ability to cope and “bounce back” from negative illness and treatment experiences. Mellins, et al. (1996) included not only social support, but the mere perception of social support as a factor that increases successful coping. Children may feel held and supported just in the knowledge that they could talk about their fears and the belief that they have people there to listen or otherwise support them if they need them. Hobbes, et al. (1985) suggested that illness severity should be measured across many dimensions taking into account physiological factors, response to treatment, psychological impact on the child, and the financial burden and general level of disruption on family life.

Not only might some children be “protected” against the negative effects of illness and treatment, some may even emerge with positive effects from these experiences. Melamed (1998) reported that at least 24% of children who receive invasive medical procedures reported improved self-esteem and coping behaviors after their hospitalization (p. 18). In a study of adolescent survivors of childhood cancer, teens seem to be not only surviving, but thriving after their cancer experience: 61% scored good or excellent on a scale of global functioning, while only 27% scored marginal or poor (Fritz & Williams, 1989, p. 213-214). This study by Fritz and Williams (1989) also found depression to be
uncommon in childhood cancer survivors. Perhaps most striking, over 60% identified at least one positive effect that having cancer had on their lives (e.g., brought my family closer together, made me appreciate being alive) (Fritz & Williams, 1989). This ability to find some personal meaning or benefit from illness and treatment has been positively correlated with adjustment in other studies as well (Fritz, Williams & Anylon, 1987). This development of positive effects or the focus on personal meaning might be interpreted as a defensive process of justification or rationalization of the trauma endured. Still, the continued and long-term adjustment with even renewed and strengthened self-esteem and confidence is striking.

Such studies serve to affirm the fact that despite being subjected to traumatic painful illness and treatment experiences, all children are not necessarily “doomed” to suffer mood disorders or other long-standing issues requiring ongoing psychological treatment. It might even be possible that at least moderate anxiety and depression for which cancer patients are at “high risk” are more normal than pathological in response to the circumstances. At the very least, it raises the question of whether or not the treatment issues for the children in these studies who were referred for treatment reflect the “normal” experiences of children living with cancer.

Limitations of the Reviewed Literature and Proposed Role of the Current Study

The theorists reviewed here can help us to understand the ways in which children grow to conceptualize their illness, the techniques they may learn and employ to help them cope and adjust, and factors that may put them at risk for or protect them against developing psychological disorders now and in the future. The limitations of the current body of research include (a) a particular narrow focus on the child’s cognitive development based on calculative rationality, (b) reliance on sources outside of the child’s
experience, (c) reliance on methods that take the language and quantitative modes of measuring used by adults rather than the language and experience of the child as their framework, (d) models that emphasize methods of control in coping that may preclude other modes of understanding and living in response to illness and treatment, and (e) a tendency to pathologize the responses of the child.

What seemed to be missing in much of the current research was an understanding of the everyday experience of the child at the center of this clinical maelstrom. Given the child’s level of cognitive development, style of coping, and intervening environmental factors, what does it mean to be a child living with cancer? What was lacking was a thorough description of the child’s experience of living with illness. The purpose of this study was to learn how children perceive themselves in the context of their illness and how their understanding reveals the world of illness through their experience. The focus was on uncovering the meaningful narratives that children create to make sense of their status as “patients” and the impact of cancer on their perception of the people, places and events in their world. My research involved speaking directly with children with cancer, and asking them to describe their own experiences through words and drawings. It is my hope that the work begun here, and continued through future qualitative studies utilizing children’s descriptions can provide psychologists, medical staff and parents with a better appreciation of the experiences of children living with life-threatening illness, thus enabling us to better understand how we can support them.
Orientation of the Present Study

Theoretical Foundations

A profound limitation of the current research is that it has not attempted to describe and analyze the experience of cancer as it is lived by individual children. This qualitative study, incorporating interviews with children about their experiences, addresses this gap in the literature. This approach offers insight into the psychological impact of these experiences that traditional quantitative studies utilizing empirical data have failed to capture. Indeed, Fiese and Bickham (1998), among others, described the need for qualitative modes of inquiry in pediatric research to provide insight into the meaning of patients’ experiences. Within the qualitative realm, existential-phenomenology provided a logical framework within which to study the meaning of the child’s experiences of adjusting to and living with cancer. Phenomenological psychology seeks to understand the implicit meanings and intentions behind actions and words. It searches for the meaning of experience as lived (Dilthey, 1927/1977; Giorgi, 1985a, 1985b). A brief description of the tenets of this approach which provided the overarching theoretical framework of this current study follows.

Central role of experience. Phenomenology asserts that as human beings we co-constitute and are co-constituted by our world. Neither has meaning apart from the other. A study of any human phenomena, then, must be a study of the meaningful relationship between humans and our world. Responding to Husserl’s call, “To the things themselves," we return directly to the phenomena in question. In this case, I began with children’s descriptions of their experience of living with cancer as evoked through their drawings of these experiences. Understanding persons’ experience helps to reveal how their particular way of being-in-the-world leads them to constitute their experience and
act in the way that they did rather than in any other way. In this study, for example, a phenomenological approach helped me to appreciate how these children have come to understand themselves through their experiences with cancer, and how this understanding leads them to respond to their illness and treatment in a particular way.

Making the experienced accessible. Heidegger (1927/1962) and Levinas (1961/1969) both spoke of the importance of language in the understanding of another’s experience. For Levinas (1961/1969), discourse was the basis for all knowledge; for Heidegger, discourse was “existentially equiprimordial with state-of-mind and understanding (p. 203).” For Heidegger, discourse was expressed through language (p. 204). So, it is through language, specifically in most existential phenomenological research the language of the written protocol and interview, that we delve into the lived experience of the individual. It was clear to me that such traditional modes of data collection and reliance upon the written and spoken word would be problematic in conducting research with young children.

Von Eckartsberg (1971) described this potential for language to express shared meaning, however, he also cautions us to be attuned to the multi-functioning of words. This second aspect and the corresponding need for careful interpretation is highlighted in research with children. School-aged children, the primary focus of the present study, have developed what McNamee (1989) described as the abilities for sustained thinking and narration which are necessary for conducting a meaningful interview. Although these children have made strides towards more fully sharing in the meanings and nuances of adult language use, certain words and expressions may yet carry special weight and meaning beyond their everyday adult usage. Additionally, school-aged children may have moments in which the vocabulary available to them falls short of describing their feelings
and experience. Practically speaking, then, how can we properly access the child’s experience?

Taking my cue from authors such as Eiser, et al (1990) and Sourkes (1995), I looked to drawings as a more “natural” and symbolic mode of expression for children. I widened the boundaries of my research by incorporating drawings into my interviews with children. Sourkes particularly described utilizing children’s play, drawings and storytelling as means of accessing aspects of their experience that children may have been otherwise reluctant or unable to describe. Children’s drawings offer a window into the creative interpretive expression of their experiences, thoughts, and feelings, often going beyond realistic or rational depictions to take on a symbolic and metaphorical quality. Drawing techniques have been used to assess levels of anxiety or depression in hospitalized children or as a means of play therapy in children referred for psychological or psychiatric consultation. I felt that using drawings as a point of entry into the world of the children in my study would provide a window into the everyday world of the child living with cancer. My interviews began with asking children to draw aspects of their experience of living with cancer (i.e., drawing a picture of themselves in both hospital and family contexts). As we took up these drawings as a source of discussion about their experiences, I took care to be guided by my participants’ language, reiterating key words and expressions to elicit further clarification. Using children’s drawings as the focus of our conversation had the added benefit of involving children as co-creators, engaged with me in the project of making sense of the pictures and the experiences they represent rather than once again reducing them to mere subjects of medical, or in this case, psychological study.

Dilthey (1927/1977) wrote that, “The understanding [Verstehen] of other persons
and their expressions of life is based upon both the lived experience [Erlebens] and understanding of oneself, and their continual interaction (p. 123).” The understanding of such lived experiences helps guide the method of phenomenological psychology. It was precisely this goal of seeking a better understanding of the child’s lived experience of cancer that motivated the current study. In asking children to draw pictures of themselves as “self-portraits” and in varied contexts such as the hospital or home, they informed me beyond the physical reality of their experience of the Lebenswelt, the life-world that is their relationship to the physical environment of the places in their world. In the process of drawing, children (and adults) may devote more time and detail to certain aspects of a drawing, indicating their importance to the child. In a self portrait, for example, a child may emphasize certain features and de-emphasize others. Moss (1989) wrote of such aspects of drawing and says, “A clinical psychologist interprets such emphasis symbolically ... the picture is built up around those parts of the body that have a special relation to the world of things and of other people” (p. 67-68). My task in the present study was to identify these areas of symbolic emphasis and to uncover their relationships and meaning in the child’s world of living with cancer.
Participants

Participants included five children (three girls and two boys), ranging in age from 7 years to 10 years (mean age = 9). Initial diagnosis of cancer in the participants ranged from 7 months to 24 months prior to their participation in this project. Cancer diagnoses included Acute Lymphoblastic Leukemia (ALL) (n=3), Rhabdomyosarcoma (n=1), and Inflammatory Pseudotumor (IPT) of the chest (n=1). Ethnic groups represented were Caucasian (n=3) and Hispanic (n=2). All participants were being treated on an outpatient basis at the time of their participation in this project. Two additional participants completed the interview process but were omitted from the final analysis after failing to complete one or more of the drawings as instructed, making it extremely difficult to include data from these interviews in a comparative analysis with the other participants.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Type of Cancer</th>
<th>Time Since Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alexis</td>
<td>7</td>
<td>F</td>
<td>Caucasian</td>
<td>rhabdomyosarcoma</td>
<td>15 months</td>
</tr>
<tr>
<td>Junie</td>
<td>8</td>
<td>F</td>
<td>Hispanic</td>
<td>acute lymphoblastic leukemia</td>
<td>2 years</td>
</tr>
<tr>
<td>Steve</td>
<td>10</td>
<td>M</td>
<td>Caucasian</td>
<td>inflammatory</td>
<td>1-1/2 years</td>
</tr>
<tr>
<td>Harry</td>
<td>9</td>
<td>M</td>
<td>Caucasian</td>
<td>acute lymphoblastic leukemia</td>
<td>7 months</td>
</tr>
<tr>
<td>Crystal</td>
<td>10</td>
<td>F</td>
<td>Hispanic</td>
<td>acute lymphoblastic leukemia</td>
<td>9 months</td>
</tr>
</tbody>
</table>

Table 1: Participant demographic data

Participants were recruited from the Center for Cancer and Blood Disorders at Children’s Medical Center of Dallas in Dallas, Texas (see Appendix G for advertisement used to recruit participants). Eligibility criteria included (a) children aged 7-11 years, (b) English speaking, (c) in sufficiently good medical condition to be able to respond to both written and oral instructions and questions, and (d) agreement of a parents and child to the child’s participation in the study. Potential participants and their parents were informed of the general purpose and procedures of the research and invited to participate by myself or by
their Child Life Specialist. Those who met the above criteria and who expressed interest were contacted by me and fully informed regarding the purpose and procedures of the study. Written consent for participants’ participation was obtained from each child’s parent. A parent was also present while the assent for participation was read, any questions were answered, and assent obtained from the participants themselves (see Appendix H for consent and assent forms). Both participants and their parents were informed that at any time during the interview process they could choose not to continue the interview and to withdraw from the study. Resources were provided for referral to all parents at the conclusion of the interview.
Data Collection

Consenting participants were scheduled for a one hour meeting with the researcher aimed to coincide with a regularly scheduled visit to the outpatient clinic at Children’s Medical Center of Dallas. Interviews were conducted privately in a hospital playroom, unoccupied treatment station, or other private area at the hospital clinic. During the interviews children were asked to complete a series of five drawings and to respond to short semi-structured questions based on those drawings (see Appendix H for interview guide). Children were asked to draw and speak about their experiences to help explain to myself and others “what it is like to be a kid with cancer."

The main topics chosen to structure the interview reflected my specific research questions regarding how the child experiences living with cancer, particularly the child’s perception and co-constitution of self and world. In order to practically access these aspects of their experiences, children were asked to complete drawings responding to my basic research questions. (1) In order to determine how children with cancer see and identify themselves, each child was asked to draw a self-portrait and describe him or herself. (2) In seeking to explore how children with cancer perceive themselves in their role as patient in the context of the hospital and clinic and to identify the child’s co-constitution of self in relation to physical illness and the environment (world) of their illness and treatment, each child was asked to draw a picture of him or her self in the clinic or hospital. (3) In seeking to determine which challenges posed by illness and treatment are of particular concern to children with cancer, each child was asked to draw and describe the “worst” thing about having cancer. (4) In order to help identify what strengths, resources, persons or techniques children with cancer perceive to be the most
important in meeting the challenges posed by their illness and treatment, each child was asked to draw what “gets you through the tough times.” (5) In order to uncover how children with cancer perceive themselves in the context of and relationship with their family, each child was asked to draw a picture of the child and his or her family (based on the Kinetic Family Drawing, Burns & Kaufman, 1972). Finally, throughout all the drawings I looked to identify the narratives, metaphors and imagery that my participants used in describing their experiences.

These drawings and responses provided material for the children and me to explore together in coming to better understand their experience of living with cancer. The structured drawing topics were utilized as a guide to ensure that the interviews covered common ground, though each participant certainly brought his or her own unique experiences and responses to the interview. After each drawing children were encouraged to talk about and further describe their pictures. I asked follow-up questions to request elaboration and clarification regarding participants’ drawings and remarks, using the participants’ language whenever possible.

Participants were reminded that if at any time they had questions or wanted to talk more that we could talk through their thoughts and feelings. They were also reminded of their right to end their participation at any time for any reason. None of my participants chose to end their participation during or after an interview. Both a parent or guardian and a child life specialist were accessible during the interviews in case a child needed additional emotional support. During the interviews none of my participants appeared to need nor did they request that additional support. However, I do believe that the knowledge that this support was available to them helped put them at ease. I informed all participants and their parents that a play therapy follow up session with a
child life specialist could be arranged should the child show signs of emotional distress during or after the interview. Again, during the interview no participants showed signs of distress and, as of this writing, no participants contacted me regarding an additional play therapy session. At the end of the interview, the purpose of the study was reviewed with both participants and their parents. Participants and their parents were given the opportunity to discuss any questions or concerns they had with me at that time. An informational flyer detailing contact information for individual or family counseling referrals was provided to all participants and their families following the interview. None of the participants was involved in a psychotherapeutic relationship with me at any time prior to or following the interviews.

The research interviews were audio taped. At the beginning of each interview I allowed participants to speak into the tape recorder then rewind the tape to hear their own voice. This served as an initial ice breaker and hopefully put participants more at ease with the presence of the tape recorder. During the reading of the assent form, I had explained the concept of “confidentiality” to participants by explaining that they would be allowed to choose their own “code name,” and that when I typed up the interview and wrote up my research I would only refer to them by their “code name” so that no one else would know it was them. Participants seemed to enjoy and were often quite creative in choosing their own pseudonyms. During transcription all names and other identifying information were indeed deleted or changed to protect the confidentiality of participants.

Data Analysis

Most research in the existential-phenomenological tradition has as its ultimate goal revealing the essential structure of a particular lived-experience. My participants were not, however, asked to respond to a single question or to describe a single experience of a
particular phenomenon. Instead, interviews centered on children’s drawings – visual representations of their experiences which included actual people, places and events they have encountered as well as imagined possibilities. At this point my phenomenon called me to break with the structural analysis of traditional existential-phenomenological research. Allowing my phenomenon and data to guide me, my method for analyzing data in this study evolved into a twofold analysis of both visual data represented in the drawings and verbal data represented in the transcribed interviews. The case-study analysis culminated in Narrative Analyses which interpret each child’s narrative, that is their story of living with cancer as told to me through the drawings and interview. The analysis concludes with a Comparative Analysis which examines both common and divergent themes across the participants’ varied experiences.

Phenomenology recognizes that as researchers we inevitably participate in not only the form but the content of our findings. With this in mind, I began by attempting to identify and make explicit my own a priori assumptions (see Explication of Assumptions) which served to continually remind me of my participation in the research. As discussed by Churchill and Wertz (1985), this initial process of identifying preconceived notions aids researchers in allowing “conceptuality [to] be informed by the phenomenon rather than dictating on the basis of assumptions and preconceptions (p. 553).” The goal, however, is not Husserl’s ideal of a complete bracketing of assumptions such that one might clearly (objectively) see and describe the phenomenon at hand. Rather, the purpose is to allow researchers to be aware of and acknowledge the presuppositions that are the ground upon which the figural phenomenon emerges.

*Analysis of drawings.* In preparing to analyze the drawings, I referred to existing research and literature regarding the interpretation of children’s drawings. As an example,
for the second drawing participants were asked to draw themselves in the hospital or clinic. This was a modification of Clatworthy, Simon and Tiedeman’s (1999) Child Drawing: Hospital Instrument. Rather than instructing children to “Please draw a picture of a person in the hospital,” as in Clatworthy et al.’s instrument, the children in this study were instructed to “Please draw a picture of yourself in the hospital or clinic.” Because of the alteration in the basic design of the instrument, and its original intent to measure anxiety in a hospitalized child over time, it did not make sense to simply transpose the method of scoring and interpretation onto my data. In my own analysis I followed the manual’s guidelines to aid in interpretation where appropriate (i.e., in analyzing the position, action, proportions of the figure, color, placement, presence or absence of hospital equipment, exaggeration or deemphasis of body parts, and shading). Certain measures that were interpreted by Clatworthy et al as signs of health or illness in the instrument’s original “fantasy” picture of a person in the hospital, could be interpreted differently for my participants as they drew scenarios which may have contained elements of both fantasy as well as remembered events (i.e., the child may draw herself in bed not necessarily because of heightened anxiety, but in response to the fact that she was confined to her bed during the time in the hospital she is depicting). The basic categories of analysis were used as a guide but did not assume that the total results, including anxiety score, from this instrument would be relevant to my varied use of this drawing technique.

In analyzing the content of the drawings, I also looked to research such as Kellogg’s (1979) extensive catalogue of children’s human figure drawings as a reference to the age-appropriate characteristics of children’s drawings and abilities at different ages. The House-Tree-Person Technique (Buck, 1948), though originally developed for use in
gathering data on intelligence in adult participants, provided guidelines for analysis of proportion, detail and dominant depictions of houses, trees and persons in children’s drawings. The content and themes in my participants’ drawings of the “worst” thing about having cancer were compared with the hospitalized children referred for psychotherapy in Sourkes’ studies, who were asked to draw the “scariest experience, thought, feeling or dream that you have had since you became ill” (1991, p. 90). In interpreting the imagery expressed in the drawings, I was informed by Domino, Affonso, and Hannah’s (1991) description of metaphors often used by pediatric oncology patients including expression of moods such as pessimism, future optimism, and images of war (a frequent image used by professionals in immunology to describe the body’s immune system’s “battle” to fend off cancer cells).

Each of these individual authors and their tests provided a backdrop for the evaluation of drawings in my study, however, with the exception of the Kinetic Family Drawing (drawing #5), the drawings my participants were asked to complete were chosen to reflect my specific research interests. Therefore I did not follow the prescribed method of administration and scoring of these alternate tests. Additionally, tests such as the Child Drawing: Hospital and Draw-A-Person, when completed by children in hospital, have been primarily used as tools to diagnose anxiety, depression and pathology and to monitor such disorders over time. In this case, the use of drawings opened the child’s world – the people, places, and things as well as hopes and fears that are the context for his or her experiences – and provided a basis for exploration of that world in dialogue with the child. As a reflection of these goals, I wanted my analysis of the drawings to go beyond a summation of normal and abnormal structural and stylistic details and their ability to predict disorder in the child. Tharinger and Stark’s (1990) research on
qualitative holistic evaluation of drawing tests served as a model for me on this point. Tharinger and Stark focused on the rater’s holistic impression and interpretation of elements in children’s drawings as they relate to one another and to the meaningful whole of the drawing as understood within the context of the child’s experience. In integrating these individual elements into a coherent and meaningful interpretation, Tharinger and Stark recommended that “the clearest sense of these characteristics [is to be] gained through placing oneself in the drawing, preferably in the place of the child” (370-371). This qualitative method of interpretation proved valuable in evaluating the drawings and integrating the understanding of these drawings into my understanding of the phenomenon as a whole.

I began my analysis of the drawings by spending time reflecting on each drawing to gain a sense of the whole, including the mood, content, and action. To aid in efficiently identifying relevant elements in individual drawings and in identifying common and divergent themes across participants I developed a Drawing Analysis Worksheet. Here I analyzed drawings with an eye toward making sense of specific structural details in light of their meaningful place in participants’ experiences. I completed an Drawing Analysis Worksheet for each drawing. I identified outstanding and thematic elements in individual drawings and throughout each participant’s series of drawings. I paid special attention, for example, to children’s changing depiction of self as portrait, in the clinic, and involved in the “worst” part of having cancer. This progression seemed to reflect children’s imagining of self and experiences within the changing context of “having cancer” and being a patient.

Analysis of interviews. In analyzing interview data gleaned from discussing the drawings with the children, I began with the basic empirical-phenomenological method
developed by Giorgi (1985a, 1985b). This approach entailed collecting descriptions of experience, as discussed above, and analyzing these data in search of implicit meanings, in this case of the experience of the child living with cancer (Giorgi, 1985a, 1985b). Once I conducted and transcribed the interviews, reflection on the data began. Reading and rereading each interview to get a sense of the whole, I divided the transcript into meaning units – that is, manageable units which expressed discrete movements of psychological meaning within the whole of the narrative. In demarcating these meaning units, I sought to remain aware that they are, as Wertz (1985) described, “meaning-unities-for-the-researcher” (p. 165). That is, my own preconceptions, judgment and interests are naturally reflected in the themes I described as well as in the way I organized these themes into workable units. These meaning units were restated more or less in the participant’s language. In the next step, the development of Individual Phenomenal Descriptions, I discarded redundant statements, and regrouped relevant units to reflect questions and themes that emerged through the interview (Wertz, 1985, p. 169). Finally, in composing individual Psychological Descriptions, I sought to determine and explicitly state the implicit meaning of these themes in light of the child’s experience of living with cancer. Here themes and meanings are expressed in more psychological language. While I indeed followed all of the above steps, the process was not always linear. I often had insights at other times or in other settings, that I used in re-working my analysis.

Having completed this analysis, I sought to re-story the individual experiences including both the implicit meanings and metaphors that were revealed through the children’s drawings and descriptions of their experience in Individual Narrative Analyses. I looked to discover how the units of both the drawings and interviews related thematically to one another and to what they revealed about the meaning of these
children’s experiences. This synthesis is not a traditional Situated Structure in that it does not attempt to define the essential structure of a discrete experience. Rather, it is meant to be a narrative of the child’s experience, while unfolding themes and meanings implicit in the child’s naive description. As one of the goals of this project was to address a gap in the current literature which overlooks the individual experiences of children with cancer, I found individual Narrative Analyses best served to reveal the unique experiences and context of my participants.

Fischer’s (1971) development of individualized assessment informed my Narrative Analyses. These individualized assessments capture the spirit and mannerisms of an individual in a way that reveals the individual’s perception and co-constitution of his or her world. It was just such an individualized narrative account integrating data from the interviews and drawings that I hoped would faithfully describe and disclose the world of the child living with cancer as revealed in our shared experience of the interview. I actively sought to story these narratives in a way that described each child’s experience of living with cancer while also acknowledging the fact that the drawings and responses emerged within the context of a research interview. Emphasizing the value of attending to these individual experiences, I include the Narrative Analyses in the Results, rather than relegating them to the appendix. Finally, in a Comparative Analysis, I attended to those themes that seemed to be common across participants as well as to important differences which emerged in their experiences of living with cancer.

At the end of this process I attempted an evaluation of my work in light of my own a priori assumptions and experiences as researcher. To aid in this endeavor I kept notes detailing my reactions to and impressions of conducting the research. Once the analysis was complete, I engaged in what Walsh (1995) has described as the explication of
implicit assumptions, reflecting on my values and experiences and the way in which they may have served to shape my conclusions. For example, I examined how my own values and training as a researcher guided how I identified meaning units and grouped them into themes. Through this process, I hoped to more fully and explicitly reveal the interrelationship between the phenomenon and myself as researcher.
Flow Chart of the Research Method

1. Conduct Interview and Collect Drawings
2. Reflect on Drawing To Get Sense of Whole, Mood, Content, and Action of the Piece
3. Read and Reflect on Interview To Get Sense of the Whole
4. Transcribe Interview
5. Demarcate Meaning Units and Restate in Third Person
6. Complete Drawing Analysis Worksheet
7. Identify Outstanding and Thematic Elements in Individual Drawings
8. Identify Outstanding and Thematic Elements in each Participant’s Series of Drawings
9. Individual Phenomenal Description: Re-Group Relevant Meaning Units to Reflect Themes of the Interview
10. Psychological Description: Explicate Themes in Terms of Their Psychological Relevance for Living with Cancer
11. Narrative Analysis: Develop Edited Synthesis of Analyses of Drawings and Interview Data
12. Comparative Analysis: Identify Common and Contrasting Themes that Emerged Across Participants
Statement of Initial Research Presuppositions

Prior to a discussion of the results, I begin here with a description of the presuppositions that I brought with me to this project. These presuppositions formed my initial attitude, or approach, towards this phenomenon. As I began formulating research questions, I attempted to make my presuppositions clear so that I could recognize them and suspend them from time to time in order to remain open to the phenomenon. As described above, I will later return to discuss the way in which my experiences of actually conducting the research came to play in shaping my conclusions.

I was first introduced to the topic of children living with life-threatening illnesses through the lives and deaths of several young cancer patients that I came to know at the Don and Sybil Harrington Cancer Center in Amarillo, Texas in 1993 and 1994. My father was diagnosed with lung cancer in the spring of 1993 and soon after began chemotherapy at the Harrington Cancer Center. My father often remarked to me how depressing it was for him to be around many of the adult patients in the cancer center. These adult patients were quiet and kept to themselves, and often seemed to my father to have “given up the fight.”

I was amazed by the difference in atmosphere between the adult and children’s areas in the treatment center. We were awed by the children and teenagers we met and their attitude towards their own illnesses. In my few encounters with them at the cancer center, these young patients seemed to be far less resigned to die, less bitter, angry, or dejected as they sat in the waiting and treatment rooms of the cancer center. These rooms were lively centers of conversation. The kids would often good-naturedly tease one another. I immediately began to wonder how they managed to cope. How were they able to seemingly take their disease in stride, with a sense of humor and courage which fewer
of the adults seemed able to muster?

Later I would spend time discussing these questions with fellow volunteers and staff at the Ronald McDonald House of Pittsburgh, a home-away-from-home for families of sick and hospitalized children. I often wondered aloud how they could endure working with dying children day after day. The answer always given was that what kept the staff, and for that matter, the families going and enabled them to endure were the sick children themselves. These children had bad days, and indeed that many of them were in extreme pain, but they seemed to live the time that they had more fully than many adults who also face life-threatening illnesses.

My own questions as I began this research concerned what it means to be a child living with a life threatening illness. How does the child, plucked out of the familiar family and school setting make sense of experiences in hospitals and cancer treatment clinics? Despite what we “grown-ups” think about how and what they understand of illness and dying, what do the children themselves think and feel? What do they find actually helps them to feel better, physically and emotionally? What can we learn from their experience?

As I began my research, I also began to uncover my own pre-understanding of this phenomenon. I was initially drawn to these young patients by their courage and unique ability to cope and go on living in the face of life-threatening illness. I also had to admit that these children must surely have bad days as well. There may be times when they do not understand or do not want to believe their diagnosis or prognosis. Where I had noted courage and determination, there would likely also lie anxiety, fear, anger, or resentment. All of these experiences converge in the child’s narrative of living with cancer. It was my initial feeling that the meaning which these children have given to their illness impacts
their response and ability to cope with being a child with cancer. I also found myself
interested specifically in the way in which these children view themselves as patients
may impact their response to living as a child with cancer. Recognizing these formative
experiences and presuppositions, I began my research striving to maintain an openness to
whatever my participants would share with me.
NARRATIVE ANALYSES

Narrative Analysis: Alexis

I first met seven-year-old Alexis and her parents in the waiting room of the clinic after an appointment. Her parents, both of whom had come to be with Alexis during her appointment, greeted and spoke to doctors and other parents in the waiting room. Alexis sat at a round table with several other children and a child life specialist talking and playing animatedly with a new Barbie doll. She had had a bone scan earlier that morning in preparation for which she had not been allowed to eat or drink for the preceding 12 hours. In the waiting room she was happily enjoying a bag of chips and juice, stopping occasionally to offer to share her chips with her parents, with one of the other children in the waiting room, and, after we had been introduced, with me. She nestled in-between her parents and snacked away while I reviewed the purpose of the study and forms with her and her parents. Her parents stopped several times during my reading of the assent form with Alexis to ask if she understood particular concepts (e.g., privacy) or had any questions. Once we had completed the forms, Alexis packed up her chips and juice, left her parents, and went with me to conduct the interview.

Alexis was first diagnosed with cancer two years ago, at the age of five. She told me the technical name of her diagnosis, “rhabdomyosarcoma,” and explained that it is a “lump,” a solid tumor. Even if she has an imperfect or incomplete understanding, Alexis is able to use medical language to interact and exchange information with the adults and medical staff around her. She did not appear to be intimidated by the “big words” used to

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2 A complete set of drawings for each participant is available in the Appendices. Throughout the Narrative Analyses, I have included details of particular drawings where appropriate in reference to their discussion in the text. Please note that these detailed pictures, unlike the originals in the Appendix, may not retain their original scale.

3 Alexis is a seven-year-old caucasian female diagnosed with rhabdomyosarcoma. She chose “Alexis” as her pseudonym after a favorite relative.
describe her illness and treatment, nor by the medical staff, whom she described as “nice.” Her ability to use the correct medical terminology and deal confidently with adults garners respect, and may encourage others to view and treat her as more mature.

As I asked Alexis for some basic information, she took the opportunity to show off a bit, providing even more information that I requested (“I can write my birthday, too!”). This seemed to hint at her interest and involvement in the project and her desire to show me that she could be a good and helpful participant. Alexis sought guidance from me, the authority figure in this situation, for spelling and for clarification of my questions demonstrating her desire to give the “right” answer. When she made a mistake, she was able to laugh, correct it, and move on. Throughout the interview Alexis laughed, joked, and otherwise worked to maintain a lighthearted conversational air. For example, while she drew she continued to smile and talk to me about what she was drawing. This move in particular served to keep me as researcher connected, involved and smiling along with her, while at the same time providing her with some emotional distance and control in this strange new interaction.

The playful openness and good humor that I witnessed in Alexis’ engagement with me and with the other adults and children in the waiting room was in stark contrast to the world that emerged through her drawings. Though she happily chatted and smiled while drawing, her drawings were monochromatic - everything drawn in black. I was so taken aback by the lack of color in her drawings that I wondered if I had not made it clear that she was free to use all the crayons and broke with my script to remind her that she could use any of the colors in her drawings. Despite my interference, Alexis reasserted that she only wanted to use black, driving the point home by telling me that she really likes black and that her “prom dress is going to be black.” The use of color in drawings is
generally taken as an indicator of children’s emotional availability, their ability to
acknowledge and own their emotional connection (positive and negative) to a given
experience, and so the absence of color would seem to point to Alexis being profoundly
guarded or disconnected with her emotional experience (O’Brien & Patton, 1974).
Clatworthy, Simon and Tiedeman describe hospitalized children who are feeling
particularly anxious as apparently lacking the energy to choose more than one or two
colors (Clatworthy, et al., 1999). Bright and light colors are often interpreted as signaling
a child’s sense of well-being and generally positive self-concept, while darker colors, like
the black used by Alexis, indicate that the artist feels extremely anxious in the face of
great stress (Clatworthy, et al., 1999). Later Alexis said that when drawing on her own
she does use different colors depending on what she is drawing. She said that she often
likes to draw colorful butterflies, flowers and rainbows. In the drawings for our
interview, however, Alexis chose to use all black because, she said, she was “working.”
Alexis’ explanation that she was “working” may speak to her desire to be involved in the
study, to give good “factual” responses that would help me and others, yet wanting to
maintain enough distance in discussing these experiences that she would not plunge into
sadness. Her monochromatic drawings may therefore result from her desire to maintain a
“working” or professional distance in her responses. Indeed, though they are a dramatic
statement on her frame of mind while drawing, it would seem from her description of
other more colorful pictures, that Alexis is not always so guarded or emotionally distant
in her drawings. She may not want to get emotional thinking about, drawing and
discussing her illness either in general, or perhaps particularly in front of and with me,
someone she had only recently met.

For her self portrait, Alexis chose to draw herself drawing (Appendix A, Figure
A1). She laughed and agreed as I noted it was an “up to the minute self portrait.” She described herself as someone who likes to draw, a prize-winning artist, who has a sense of humor (demonstrated, in part, by her tongue sticking out in this drawing). She went on to say that she enjoys biking, swimming, playing with Barbies and getting toys. These are ordinary activities for a child her age. Her continued interest in these activities may serve to help her maintain a sense of normalcy in the face of her illness and treatment. In using these activities to describe herself, she identifies herself not as sick, anxious or fearful, but as a “normal,” active, fun-loving child. She may have cancer and have to endure needle sticks and surgery, but she likes toys and activities like any other girl her age. When asked to describe how she might draw herself in the future, Alexis said she would draw herself fourteen years old and painting her nails with her cousin. Here, without peering too far into the uncertain future, Alexis describes another ordinary, fun activity she might engage in as a teenager, again emphasizing how she wants to go on with her life and enjoy the little ordinary things that other girls enjoy (e.g., painting her nails, looking pretty, hanging out with a friend).

When pressed about whether anything has changed since she has had cancer, Alexis said that she lost her hair, had bone scans, was in the hospital, and had had five surgeries. She listed these things rather matter of factly, not stopping to elaborate on what these experiences had been like for her. She simply listed them off as things she has done that others have not. She felt that these experiences made her different from other children her age who have not had cancer. She also mentioned that when she is well, she eats “lots.” When she is sick and in the hospital, she does not eat, either because she has no appetite or because, as she said, she does not like the hospital food. When she cannot or does not eat, she may lose weight and have less energy, exacerbating the differences and
symptoms she already feels when sick.

In the second drawing, Alexis again drew herself drawing (Appendix A, Figure A2). As in her first picture, she drew a picture of the her that I could see, as if to say, “You want to see me? Just look. I’m right in front of you.” For this second drawing, I had asked Alexis to draw a picture of herself in the clinic or hospital. In response, she drew the immediate environment of the table and chairs in the clinic where we sat during the interview. As I asked her about her drawing, Alexis said that she drew this picture so that “you could see everything.” Though she drew “everything” on the table in great detail (e.g., the tape recorder, crayons, water bottle), she drew nothing of the examining rooms, doctors, or even the friendly environment of the waiting room in this narrowly focused perspective. Alexis has distanced herself from the surrounding environment and procedures of the clinic. In her description of the clinic, Alexis continued to distance herself from the negative aspects of her experience, at first speaking only of the positive and mundane: the nice people in the clinic, the gift shop, and the toys she might receive after a visit to the clinic. In fact, Alexis’ own face and expressions are hidden from view in this drawing. From this overhead perspective and with Alexis looking away, we can hardly see her in the clinic at all. We cannot see a smile or a frown. All that we know is that she sits and she draws.
By drawing herself from above and facing away, she is also distanced from seeing herself and her own emotional connection to being in the clinic. Here, Alexis focused only on what was literally in front of her (the table, tape recorder, etc.) just as she later described focusing on the idea of getting a toy. This seems to allow her to tune out what she does not want to hear or see (e.g., the rest of the clinic, a painful procedure). Alexis may have this response as a general means of avoiding or distancing herself from feelings of anxiety or fear associated with the clinic, or she may have simply not been ready to enter into that emotionally-charged field with someone she had only just met.

Later, perhaps once she was feeling more comfortable with me, she began to speak of the needles, pain, and other more negative aspects of her experience. Alexis said that she does not like getting “poked” with a needle in her hand or arm for an IV. When I asked how she felt being in the clinic or the hospital, she replied, “screamy.” Alexis explained that she “screams a lot” when she gets poked by needles in the clinic. It hurts her when “they push the needles in and out and in and out.” Alexis doesn’t like it just before she is “poked,” either. She described feeling scared as she goes back and forth, looking first at the needle, then around the room. This image finds Alexis recognizing a frightening and painful event (the needle) then looking around to find something else to focus on to take her mind off her fear and anxiety. Alexis feels scared when she has to endure painful procedures and when she does not know what to do. She seems to want clear direction, or at least a clear distraction. Alexis added that she does not like it when doctors “keep you waiting.” This morning she had to wait for two and a half hours for her scan. Alexis said that the worst thing about waiting is that she gets bored. Certainly, long hours with nothing to do are very “boring” to young patients like Alexis. Waiting also likely plays into the “scary” cycle of anticipation in which Alexis knows the painful
thing that is coming but has to wait for it to happen. Finally, she added that she does not like the “gross” smell of the hospital. For Alexis, the hospital is an uncomfortable (i.e., pillows like “stones”), unfamiliar (i.e., she does not like the food, the smell is “gross”), and menacing (i.e., people “coming at you” with needles to “poke” you) place where painful procedures occur.

Although we had only just met, Alexis was eventually able to assert her own opinions and desires during the interview. Before we began, she told me that she was ready to “work,” and informed me that she would be eating and drinking during the interview. Asked if she would like to use colors other than black in her drawings, she held fast, letting me know that it was her choice. Alexis was clear and vocal about what she does not like about the hospital (i.e., needles, the food, waiting). Alexis did not seem intimidated by the professional medical atmosphere of the hospital. In fact, at one point in our interview, Alexis saw her doctor and was not shy, but instead teased him for making her wait before her earlier appointment. In her drawings, she drew herself as large as the figures of doctors and surgeons, again revealing that while she very clearly does not like the procedures, she is not intimidated by interacting with the medical staff (Clatworthy, et al., 1999). When not anticipating or undergoing a painful procedure, Alexis seemed relatively at ease. After two years, she knows what to expect from her visits to the clinic, including when it is safe to let her guard down.

Alexis laughed and jokingly whined as she drew the “worst” thing about having cancer. Alexis laughed nervously as she drew herself in-between two doctors, one with an IV needle and a surgeon with scissors (Appendix A, Figure A3). Again, Alexis appeared to use humor as a means of diffusing and distancing herself from a difficult situation, or in this case memory. She described the figure with the needle as “evil” because of the way
she drew his eye. In this picture, she said, she doesn’t know what to do. When I asked Alexis how she feels in these kind of situations, she described feeling scared when she is “trapped” in the middle not knowing what to do first.

Alexis often laughed and joked with me during the interview. In many cases she laughed while speaking of or drawing a difficult, painful, or otherwise emotional aspect of living with cancer. For example, she laughed and made whimpering noises while drawing the “worst” thing about having cancer. This trend may indicate that Alexis uses humor as a means to diffuse emotionally laden or negative situations. When she is able to laugh she is able to maintain some emotional distance from what otherwise might cause her to feel anxious or frightened. In this situation, at least, it served to help her maintain distance and composure while involved in the interview with me, a person she did not know very well. Along these lines, Alexis’ mother had relayed to me that when she was first diagnosed, Alexis did not want her family to use the word “cancer.” This at first appeared to be a form of denial (“if we don’t talk about it, it won’t be true”), yet as Alexis went on to tell me, she asked them to call her cancer “the horror” instead – a rather unlikely euphemism. In talking to me, Alexis always spoke the phrase “the horror” in a melodramatic tone of voice. Alexis was not denying that she had cancer, but by using her sense of humor, she was able to distance herself and others from the powerful negative emotions associated with the word “cancer.” In doing so, Alexis could still talk about her “awful” experience of cancer while diffusing the situation and allowing herself and others to face them with a smile.

Alexis’ tendency to distance herself from negative feelings and experiences was revealed in several ways throughout her drawings. Alexis’ figures (herself, doctors, family, etc.) were relatively small and her drawings on the whole took up relatively little
Research on children’s artwork indicates that children who are feeling anxious tend to draw small figures who appear overwhelmed by their environment, either by other objects, or by the environment of the paper itself (O’Brien & Patton, 1974; Handler & Habenicht, 1994; Clatworthy et al., 1999). Alexis’ small figures indicate that she is feeling anxious or perhaps threatened. This anxiety could either be a more general response to having cancer and undergoing treatment, or more specifically, to speaking about these experiences with me, a relative stranger to her world. The figures themselves could signal that Alexis felt anxious in the face of feeling small and overwhelmed, or they could be themselves have been an attempt by Alexis to literally distance herself from the anxiety-laden experiences she was drawing by making them distant – a safe distance from her, the artist. As she drew more and more fearful experiences (i.e., being in the clinic, waiting for surgery, in surgery), there is an accompanying shift in her physical position in the drawings (sitting with support to lying immobile), and in her mood and the tone of her drawings reflected in the facial expressions (smiling, worried, expressionless) Alexis drew for herself (Burns & Kaufman, 1970; Machover, 1949, Tharinger and Stark, 1990; Clatworthy, 1999). The shift in position reflects the reality in Alexis’ world of the posture she is called to adopt as a patient (though she could have chosen to draw herself standing, in reality as in this drawing, a patient lies on an operating table). This shift from standing, to sitting with support to lying down, also indicates a shift in Alexis’ feelings of losing some of her independence and ability to take positive action in these situations (Dileo, 1970; Clatworthy, 1999). Instead of actively engaging the world, as she draws herself sick and in treatment, she draws herself more and more passive and dependent upon, or at the mercy of others.
As she drew the fourth drawing of what helps to get her through the tough times, Alexis again talked to me about what she was drawing (Appendix A, Figure A4). For most of my participants, this drawing of “what helps you get through the tough times” tended to be one of the most happy, optimistic drawings. Here, however, Alexis drew what helped her in the very midst of a specific “tough time:” her first surgery. Indeed, she described this drawing as “violent.” Alexis described feeling scared and nervous before her first surgery. She pointed out that the doctor figure in her drawing has a knife and scissors (something Alexis associates with the medical-surgical lingo of “cutting”). She described the surgery where he would “cut [her] open” and remove the tumor with a knife. In this drawing, Alexis drew herself lying down on the operating table, and for the first time, omitted her arms, an indication that in this situation Alexis felt passive and defenseless, with no way to stop what was happening to her (DiLeo, 1970; Levenberg, 1975; Clatworthy, 1999).

In the drawing, Alexis is expressionless, anxiously frozen and looking straight ahead at a toy. Indeed, this toy is the first true “barrier,” an object that draws distance between Alexis and another figure in her drawings, in this case, the surgeon (O’Brien & Patton, 1974; Tharinger & Stark, 1990). Alexis explained that what helped her get
through her first surgery was the promise that she would get a toy once it was over, which she did. She felt happy when she was told she would get a toy after her surgery. She focused on that to get her through. She agreed that in this picture the teddy bear is close to her eyes so that she can’t see the surgery. She focused on the toy she would get afterward instead of on the surgery underway. Here the image of the teddy bear stands out amidst the doctor and medical equipment. It is a figure from the “normal” world of childhood, seemingly out of place in this sterile medical environment. Focusing her whole imagination on getting a treat, a toy, and playing with it just as she might have done or might someday do when she is no longer in treatment, helps Alexis get through the anxiety, fear and pain of surgery and other painful procedures. Similarly, Alexis added that it is also hard to get IV’s in her hand because they hurt a lot – except, she continued, when she gets a toy. Alexis agreed that it makes her happy that her parents want to do something special for her like getting her a toy after she has had a shot or a scan. She does not usually have something in particular that she wants. Instead, Alexis said, “They love me - I get to pick it!” Alexis’s parents show that they love her by letting her pick out a toy. In this way, receiving a toy is receiving a token of her parent’s love and care – an acknowledgment from them that she made it through a frightening and painful procedure.

For her family drawing, Alexis drew a picture of her mother, herself, her brother, and her father “playing Monopoly” (Appendix A, Figure A5). Alexis said that in this drawing her dad does not want to, but is trying to get a piece that fell under the table while her brother smiles because he didn’t have to get it. Alexis says that she likes playing games better than anyone else in her family. She gets to play only when they agree to play with her. Her family doesn’t play games together very often, but she agrees that she likes it when they do. She enjoys bringing the whole family together to do
something fun that she enjoys. This drawing of her family close together and engaged in a common activity reveals Alexis’ view of her cohesive family unit. In this drawing, she describes that they have all come together more for her, the one who loves to play games. She enjoys being the center of their attention and being the one who brings them together. Alexis says that she and her brother play together a lot. She likes her brother and thinks he is really nice. She first says that he sometimes saves her life, then corrects herself saying that he would save her life. In this picture, Alexis and her mother have particularly big smiles. Her mother is drawn with large eyes, smiling and watching over the rest of the family. Alexis agreed that everyone in her family is pretty close the way that she drew them close together in her picture. During the interview, Alexis proudly pointed out that both her mother and father were there at the clinic, supporting her.

Indeed, whether it is mom watching over her, dad playing games and picking up errant pieces, or brother, willing to save her life, Alexis described each of her family members as being there for in their own way her during her illness. Alexis agreed that having cancer has changed her life. She explained that her life has changed “in a good way” because now she gets toys after she gets a shot or has a scan. Alexis added that having cancer has made her special. Alexis explained that since she has had cancer she has had “a lot of attention” which has made her feel “special.” Alexis likes that she has had lots of attention. The fact that she said having the attention made her feel special may indicate that she did not feel (or does not remember feeling) as special or that she had as much attention before she had cancer. Given that Alexis now seems to associate gifts with attention and love, she may need extra reassurance that she is still loved and special if and when she completes her treatments.
Narrative Analysis: Junie. From my first communications with eight year old Junie and her mother, they both seemed considerate and enthusiastic about their involvement in this project. In scheduling our interview, Junie’s mother said that Junie usually felt sick and tired after a day of receiving chemotherapy. They offered to meet me at the hospital on an “off” treatment day instead so that Junie would be feeling better for the interview. We agreed to meet the next week. When I met Junie, she was quiet, but smiled broadly as we were introduced. Though she had just come into the hospital from the warm weather outside, I noticed that Junie wore a sweater, identifying herself as a veteran of the chilly air-conditioned climate of the hospital. Her mother let me know that Junie was feeling a bit nauseous and had a sore mouth and throat from her chemotherapy treatments, but that otherwise her energy level was relatively good. Junie sat snugly on her mother’s lap hugging a favorite stuffed animal as I reviewed the consent and assent forms with her and her mother. Junie listened attentively and nodded as I explained the study. When I asked if she had any questions for me she shook her head, then looked to her mother to see if there was anything she thought Junie should ask. As we prepared to begin the interview, Junie kissed her mom goodbye and settled in next to me at a table in the playroom.

As we began the interview, Junie was quiet. At first, when she did talk, she spoke from behind the sleeve of her sweater. This may have been a bashful habit, or a self-conscious attempt to hide any sores in her mouth from the chemotherapy. In these early interactions, Junie came across as quiet and shy, even a little anxious or unsure of herself. For her first drawing, the self portrait (Appendix B, Figure B1), Junie drew herself bright-eyed and smiling in a bright purple shirt. Junie’s use of a wide range of color and space in

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4 Junie is an eight-year-old hispanic female diagnosed with acute lymphoblastic leukemia (ALL). She chose “Junie B. Jones” as her pseudonym after the main character in one of her favorite series of books.
this and other drawings revealed a much more expansive style than I would have expected from her at first. Junie did not draw small figures overwhelmed by their environment. Instead, throughout her drawings Junie depicted relatively large, well-proportioned figures, suggesting that she was reasonably self-assured and confident even in the midst of her interview (Handler & Habenicht, 1994; Clatworthy et al., 1990). Later, Junie smiled and agreed that she used as much space as she needed for her drawing. Junie said that she is kind of shy when she first meets people. However, she smiled and agreed that her drawings are not small or shy just as she is not always quiet or shy. Junie’s use of color and her depiction of her self smiling in this and other drawings reflects her happy personality and overall positive attitude (Burns & Kaufman, 1970; Clatworthy et al., 1999). I asked Junie to tell me about her drawing, and she shrugged her shoulders, saying, “it’s just me.” When asked to describe herself, Junie did not focus on her physical condition, her cancer or treatment, but rather on the normal interests and activities that any young girl her age would enjoy. She told me that she likes animals and has three pets – two dogs and a fish. As I would learn during the interview, Junie feels well loved and cared for and in turn enjoys loving and caring for her pets. Finally, she added that she likes to read and sing.

Junie, eight years old at the time of our interview, said that she was six when she was first diagnosed with leukemia (acute lymphoblastic leukemia, or ALL). Junie explained that leukemia is a cancer in the blood. Asked to describe herself before she had cancer, Junie focused on her physical appearance, saying that before she had cancer she had longer hair. Her hair was straight, but Junie does not know if it will be straight when it grows back. The changes Junie has undergone while she has been ill, including the physical changes such as losing her long hair, may remain with her as she moves toward
recovery. She may literally look very different in the future than she did before her illness and treatment. Junie is a different person for having lived with cancer. Junie also explained that before she had cancer she did not have a lot of bruises from needles and IVs. These are again the physical signs of what Junie has endured. She described the bruises themselves as sometimes tender. Beyond that, they are a visible reminder to Junie and potentially to others that she lives with cancer. During the interview Junie did not draw attention to her illness, instead choosing to emphasize her normal activities and interests. However, she recognizes that her hair loss and bruises do make her stand out as different – they identify her to others as a girl living with cancer.

For the second drawing of her in the clinic (Appendix B, Figure B2), Junie drew herself sitting on the exam room bed waiting for a check up. She worked to draw the detail of the bed and a stool like those found in the exam rooms. Junie said that when she is in a room waiting for a check up, as she is in this drawing, she feels scared, but sometimes “not so scared.” She explained that she feels scared when she gets a “back shot” (a spinal tap or bone marrow aspiration) makes her feel scared, but she feels not so scared when she does not get a “back shot.” This depiction of Junie smiling in an otherwise anxiety-provoking situation (examination room where she often has blood drawn, or receives shots) may in part serve to mask the anxiety Junie feels reflecting on her experiences in the hospital clinic (Clatworthy et al., 1999). In this drawing of the clinic there is a noticeable lack of anything frightening – there are no needles, no medicine, and no doctors or nurses to administer them. Junie laughed and agreed that the fact that she is alone in her clinic drawing means that there is nobody coming at her with needles. For this drawing Junie focused on what it looks like in the clinic not on the needles and things that happen to her there. As in her first drawing, Junie drew herself wide-eyed and
smiling broadly. Junie has distanced herself from the anxiety-provoking aspects of the clinic. She has drawn a great physical representation of the clinic (what the clinic “looks like”), including a wide range of color and detail, without including the negative events or feelings she has experienced there.

Although Junie seemed to be generally positive, even when reflecting on living with cancer, she pulled no punches in describing the “worst” parts. Rather than choose only one thing, needles or being in the hospital, she included both and emphasized that both experiences are extremely difficult for her. So, for her third drawing of the “worst” things about having cancer (Appendix B, Figure B3), Junie drew herself being in the hospital and about to get a shot. Junie laughed when she realized she had not left enough room for the second figure in her drawing. She drew the figure, a nurse, anyway, allowing her to overlap the television. Junie explained that she drew the nurse coming in with a needle while Junie is watching TV. Ordinarily, transparency (seeing through one object to another) might be a sign of disturbance (Clatworthy, et al., 1999). However, in this case Junie was not yet nine years old, the age at which transparency takes on greater significance, and the transparency seems more the result of poor planning combined with Junie’s desire to maintain all the correct proportion and location of figures and items in her scene. Junie drew herself looking much the same as in her previous pictures, with the exception of a more neutral expression. Here her smile is gone, indicating that Junie was able to at least somewhat acknowledge the more negative feelings associated with the subject matter of this drawing. Though on the whole this picture and its mood are more subdued, she still used a range of colors, which again signals her ability to connect with and own the negative experiences associated with her illness (O’Brien & Patton, 1974; Clatworthy et al., 1999).
For Junie, the worst thing about having cancer right now is the immediate physical pain of the needles used for blood draws, chemo treatment, and bone marrow aspirations. “Needles hurt,” she explained. Junie discussed the many ways in which she regularly has to cope with the pain of needles: getting “a finger poke most every day” at the clinic, getting bruises from the needles, and getting “back shots.” Getting a “back shot” (a spinal tap or bone marrow aspiration) makes Junie feel particularly scared because it “hurts a lot.” She explained that when she gets a back shot they give her some “sleepy medicine” and she goes to sleep. Junie is relieved to know that she does not have to be awake during this procedure. However, the anxiety she feels about the associated pain before and after the procedure, and likely over the need for this test and anticipated results, keep it at the top of her list of “worst” things about having cancer. In the drawing, Junie knows that the nurse, and needle, are coming, but she has distracted herself by watching TV. Her decision to depict the moment *before* getting a shot may be an attempt to give herself some distance from that traumatic event. However, during the interview she also spoke about feeling scared and anxious *before* a procedure. The tension of that moment – trying to distract herself while she knows what is coming – *is* captured here.

Junie adds that she does not like feeling sick and having to be in the hospital. The hospital is an unfamiliar environment for Junie. When she is in the hospital, she is removed from the safety and security of home. Being in the hospital also signals that she is sick and weak and must stay in bed to receive treatment and rest. Even towards the end of a hospital stay when she is feeling better, as a patient, she spends most of her time in bed. So whether she is feeling poorly or not, Junie says that in the hospital she is “lying down a lot.” Junie does not like staying in the room at the hospital. Junie misses seeing friends and others she normally interacts with when not sick and in the hospital.
She explained that she has some other visitors, but not a lot. She explains that it is “boring.” This again points to Junie’s normally happy and energetic personality. She does not like being kept “down” by feeling sick or by having to stay in bed at the hospital. Junie drew herself lying in the hospital bed wearing her own clothes – not a hospital gown. In this way, Junie expresses her individuality even while in the hospital environment. This seems to indicate that she does not totally identify herself with the role of the patient. In this drawing, Junie does not wear a generic exposed hospital gown, but rather her own clothing – what she wants to wear. In her regular clothes, she could, in effect, be just any kid, perhaps someone just visiting the hospital. She could get up and go at anytime since she is dressed and “ready” to go and be about her regular activities and life. This seems to reflect not only Junie’s retaining her sense of self, but specifically, her sense of herself as just a regular child and her desire to leave the hospital behind and (once again) be care- and cancer-free.

Junie said that the people at the hospital clinic are nice. She knows that whether she has to have a “back shot” or just a routine examination, she can count on the people in the clinic to be nice. Junie added that she likes the playroom at the hospital. The playroom in a safe, needle-free, environment in which Junie has the opportunity to get up and out of bed, interact with other adults and children, and engage in normal activities that she enjoys – creating arts and crafts.

Junie recognizes that she does not always have to be scared in the clinic and hospital. As a result, she does not seem to generalize her fear or anxiety about these painful procedures to all of her experiences at the hospital. She can relax, or at least be “not so scared,” when she knows she is in for a more routine checkup or blood work. She does not expend time, energy, or emotion worrying about a trip to the hospital unless she
has to (unless she knows she is going for a “back shot”). Otherwise, she can focus on visiting a playroom, watching tv, or on the all the nice people who care for her at the clinic. Being able to distinguish these events and her accompanying emotions, helps to distance Junie from the negative thoughts, feelings and experiences until she has to face them. Then she can face them and go back to her normal life. In this way, knowing what to expect from visit to visit has helped Junie keep from dreading and anxiously fearing everything associated with the hospital.

Junie’s self portrait and drawings of herself in the clinic and hospital showed a steady progression from standing, to sitting, to lying down. This progression is realistic based on Junie’s experience of what is expected of her in the hospital: patients do have to sit on the examining table when they are in the clinic for a check up, and lie in bed when checked into the hospital. Junie agreed that standing, sitting and lying down in her drawings reflect how she has to start sitting or lying down when she is tired and doesn’t feel good. This posture of the patient also reflects a move from more active to more passive. Again, this is based in part on Junie’s waning physical strength, such that she feels the need to sit or lie and rest, as well as on the expectations of others regarding her role as patient. When she is a patient, Junie waits to be operated on, treated and cared for by others. She agreed that when she is sick and has to lie down, things like shots happen to her instead of her going out and doing the things she wants to get up and do.

At first, Junie came across to me as a bit timid. Throughout the interview, however, she was able to ask for what she needed and to use the materials at her disposal to her best ability. Though she had frequently turned both to her mother and to me to ask for guidance, Junie was not afraid to disagree with me when she felt my interpretations fell short of or conflicted with her experience. After drawing herself as the only figure in
the first three drawings, I asked if she felt lonely or isolated in the hospital. Junie said no, that her mother was always with her. Indeed, in her clinic picture, though she is alone, she has taken care to draw a stool which leaves a place in the room for another (her mother, a doctor or a nurse) to join her. In her drawing of the “worst” part of having cancer she turned the paper just the way she wanted it, indicating Junie’s ability to manipulate the environment when necessary. Though she did ask if this move was ok, she did so only after she had already turned the paper and begun to envision just how she wanted the drawing to look.

For her fourth drawing of what has helped her get through the tough times (Appendix B, Figure B4), Junie drew herself and her mother with their arms outstretched about to hug one another. To help her get through the tough times, Junie says that her mom holds her hand and sits beside her. Junie said that she feels better when she holds her mom’s hand. She also likes that her mom stays with her in the hospital. Junie’s mom cannot make the pain of the needles or her cancer “all better.” What does help Junie to feel better is holding her mom’s hand and knowing that she is there beside her – she knows from these simple gestures that she does not have to face living with cancer, the needles or the hospital stays, alone. In this picture, Junie depicted her close relationship with her mother by drawing their two figures attending solely to one another and reaching out to embrace. Her mother was the primary focus of Junie’s discussion of this drawing, and was depicted here as caring, and accessible. It is interesting to note that Junie seems to identify with her mother, having drawn a heart on her mother’s shirt just like the heart she drew on her own shirt in this and other drawings. In this picture Junie depicted a close mutually caring relationship with her mom, the fact that she is about to hug and comfort her mother is equally clear. Though Junie’s focus here was on the ways in which
her mother helps her, I can imagine that the closeness they share has also helped her mother cope with Junie’s illness and treatment. Serendipitously, during the interview Junie’s mom came in, gave Junie a kiss on the head and asked how everything was going. Junie nodded and said everything was fine. Her mom told Junie that she was waiting right outside and that she would see Junie soon. Junie smiled and waved goodbye as her mom left the room. We returned to the interview, and Junie continued by adding that her dad also helps her by doing the same kinds of things as her mom (i.e., holding her hand, being close). Junie agreed that having her mom and her family close to her and supporting her is a big part of what helps her. Junie knows that her mother and father love her and will be with her each step of the way.

For her final drawing, the drawing of her family (Appendix B, Figure B5), Junie drew herself, her mom and her dad calling their two dogs. In the drawing Junie and her family are going to go play with the dogs, an activity Junie said she enjoys. It may also be a welcome diversion from Junie’s illness for her and her family to be focused on taking care of the dogs. The dogs are something that depend on Junie’s care and attention, giving her the opportunity to be the caretaker for a change. In her picture, she and her parents are standing together and focused on a common activity. Just as Junie described normal everyday activities that she enjoys, she describes very ordinary things she enjoys with her family. Her focus here was on the normal everyday functioning of her family and the things they enjoy doing together. Junie says that her family likes playing with their dogs, watching movies at home, going to the movies, and going bowling together. Junie also demonstrated that she is closely attuned to her parents, describing things that they enjoy, rather than just what they do with or for her. Junie described her dad by saying that he likes computers and music, and her mom saying that she likes to visit Junie’s grandma.
Just as in the previous drawing, Junie grouped the figures of her family closely together revealing a cohesive family unit (Brannigan, Schofield & Holtz, 1982, O’Brien & Patton, 1974). This suggests that Junie feels close to and supported by her family, and likely interacts well with others in her world (Levenberg, 1975; O’Brien & Patton, 1974).

Finally, I described a game I was reminded of by this drawing in which one person stands in front of another who they trust to catch them as they fall back. Junie did not seem to have had that game immediately in mind while drawing this picture, but said she did know the game. In her drawing, each person in the family stands just in front of another member whose arms are outstretched to them. Just as in the “trust game,” Junie trusts that her family will be there to catch her when she needs them. I was also reminded of the image of Junie’s mother checking in to let Junie know she was there while Junie smiled, waved good bye, and continued with the interview on her own.

Being able to be dependent on her dependable and caring family, and on the medical staff at the hospital, has given Junie the confidence to go forward more independently as she grows stronger and older. She has been reassured by their support that she can do it.

Much of the action throughout Junie’s drawings involved potential action or
passively waiting for something to happen (e.g., waiting for her checkup, a nurse is about
to give her a shot, she and her mother are about to hug one another, the family is calling
the dogs and about to take them out to play). Similarly, her tendency to draw relatively
large eyes may also point to being vigilantly attuned to the world around her (Burns &
Kaufman, 1970; Clatworthy et al., 1999). This would seem to reflect Junie’s stance of
watchful waiting to see what will happen next. She has been receiving her treatment for
some time now. She is nearing the point at which her doctors will reevaluate to determine
if she has responded as well as expected and is ready to discontinue treatment, or if more
aggressive treatment is needed. At this point, she hopes to complete treatment within the
year, but as of now remains unsure as to what the future holds in store for her. When
asked what, if anything, might be different about her in the future, Junie said she could
not think of anything. Whatever the future holds, Junie believes that having cancer has
made her “braver.” She said that she still feels nervous when she thinks about going to
the clinic or hospital, but she is more used to it now. She agreed that she is more brave
about other things now, too. Junie has earned this bravery by making it through each step
of her illness, diagnosis and treatment. She has taken these experiences and emerged with
a new meaning and perspective on the world: if she has made it through this far, she can
bravely face whatever the future holds in store her. She has developed self-confidence
and, with the loving support of her family, stands ready for whatever tomorrow may
bring.
Narrative Analysis: Steve. When I first spoke on the phone to Steve and his mother, they both seemed very friendly and enthusiastic about participating in this study. They both asked questions about my research and seemed eager to meet me and to contribute to this work. However, the next week when I met them in person, I immediately noticed that both Steve and his mother were much more quiet and subdued than they had been on the phone. They sat close together as they listened to me read over the consent and assent forms with them.

Through Steve and his mother, I learned that just that week Steve had come to the hospital for a check up after five months of being off of chemotherapy. Steve’s doctors had informed them that his cancer had metastasized, spreading outside of the heart & lungs. They explained that none of the steroids or chemotherapy treatments Steve had been given had been able to successfully cure or “shrink” his tumor. They went on to explain that he would not survive surgery to attempt to remove the tumor. At this point, Steve and his mother were told that there is little hope for a cure for Steve. During the interview, Steve seemed to be actively trying to process and come to terms with this information. Before even beginning the drawings, Steve began to tell me the story of how he came to be diagnosed. Given what he had just learned regarding his prognosis, and his frustration over his late diagnosis, it seemed important for Steve to tell his story.

Steve first found out that he had cancer, specifically, an “inflammatory pseudotumor,” two years ago when he was eight years old. As I would come to see,

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Steve is a ten-year-old caucasian male diagnosed with an Inflammatory Pseudotumor (IPT) of the chest. He chose “Steve McNair” as his pseudonym after the quarterback of the Tennessee Titans professional football team.

I recorded quite a bit more information on Steve’s initial diagnosis than I did with my other participants. This would certainly seem to be fertile ground for future research regarding children’s experience of receiving the diagnosis of cancer and how those initial impressions may serve to shape their experience of illness.
Steve had a rather comprehensive understanding of his diagnosis, treatment, and prognosis. This is likely due to the fact that as treatment options have become more limited, his doctors have had to explain why they can’t do more. At ten, Steve is now able to understand more of the medical language and physiological processes involved in his illness and treatment.

Before he was diagnosed, Steve was really active. As he became sick, he noticed that he could not be as active as he wanted or that he would “start wheezing and coughing really bad.” Steve noticed that other kids would not be as tired as he would. He had been absorbed in the everyday world of childhood when he suddenly was not able to play the way he was used to or the way other children his age could. At that point, he knew that something “wasn’t right.” At eight-years-old, Steve was just a regular kid who had no reason to know about collapsed lungs, chest x-rays, tumors, or biopsies.

Steve’s mother took him to a series of doctors who all diagnosed him not with cancer, but with asthma. Steve said that he went to many doctors, he “wouldn’t say thousands, but more than one.” Looking back on how simply his diagnosis could have been made, Steve said that “one doctor should have done the job.” Steve believes that the doctors who were not able to diagnose his cancer were not doing their job. Steve says that these doctors never “listened” to him – to his story or to his lungs – and they never ordered a chest x-ray which would have revealed a mass. Steve described feeling betrayed by these doctors, who could have saved his life by making an early diagnosis, but who instead failed to listen, and ultimately failed him. Steve explained that his physical symptoms kept getting worse because all the while his “tumor kept growing.” Finally, they went to a doctor who did “what no other doctor did: he listened to [Steve], listened to that one side of [his] lung.” By listening, the new doctor was able to perform and
order the correct diagnostic tests to determine that Steve did not just have asthma or a collapsed lung, but a tumor.

Steve described himself as “really young” when he was first diagnosed, saying that he “did not know what was happening.” Everybody told Steve what was going on, that he had a tumor. When he was being diagnosed, he looked to others’ reactions to help him understand what was happening to him. Others, including his brother, tried to comfort him and tell him not to be scared, but Steve saw from his brother and mother’s reactions that something was seriously wrong, and Steve was scared.

Steve said that “then it got hard.” He describes the first painful tests and procedures that he had to endure at the hospital. In particular, Steve described a violent scene where they had to “stick” a tube up his nose. Steve did not know what was happening or what to expect, but he was frightened and did not want to do it. As they inserted the tube, he squeezed onto the bed rails, shouted and struggled against the nurses who were holding him down. The fact that Steve did not understand what was happening to him, why these painful tests and procedures were necessary seemed to make them all the more traumatic. Steve explained that his mom had to leave the room because it was “hurting her” to watch. Steve said that it was "scary" for him and for his mom, too. This speaks to Steve’s close connection with his mother, that he knew that it hurt her to see him in pain. It also points to the frightening experience of feeling abandoned, even if for only a moment, into the hands of the others who were hurting him. His mother was not able to make him better or to protect him from feeling pain. Steve described that once it was over, his mom came back in and gave him hugs, but he still felt sick, tired and shaky. Steve literally felt shaky after this traumatic event, but figuratively, his world had also been shaken. While no parent can ultimately protect a child from everything, or make it
“all better,” the realization of this fact brought home through such a dramatic experience could be devastating for both parent and child.

Steve had experienced a series of events in which his doctors and their suggested treatments proved unsuccessful. Steve said that they “opened him up” and found that they could not do anything because of what and where the tumor was. Steve had to undergo a series of treatments which were each ultimately unsuccessful in eliminating or shrinking his tumor. Now, as previously mentioned, Steve learned that the chemo, too, was unsuccessful as the cancer had spread outside the lung. Steve described being very “frustrated and upset” that it took so long for a doctor to finally correctly diagnose him and that there now appears to be no cure. Steve said that “if they just would have started chemo when [his tumor] was first beginning,” he never would have had to go through with all the treatments and his current prognosis. Steve explained that since they “waited too long” to begin treatments his tumor did not ”shrink away.” Again, the fact that Steve used relatively mild language and did not, for example, describe feeling angry, may indicate that he was guarding against feeling overwhelmed by such powerful negative feelings, or that he was simply not comfortable sharing those more intense emotions with someone new.

For the first drawing, his self-portrait, Steve chose to draw himself before he had cancer, “when [he] was active” (Appendix C, Figure C1). Steve said that he could have drawn himself running or jumping which would also show him as active. Steve described himself as nice. He explained that if anyone asked him to do something he would do it. Steve agrees that he likes to do things for people and help out. Steve also describes himself as ”shy,” though he contrasts feeling “shy” with being courageous, so it may be more appropriate to say the he feels “cautious” when facing a new situation or challenge.
When it comes to something he really wants to do, Steve says that he is “shy” at the moment, but then he’ll do it. Struggling to understand what has happened to him and what is now expected from him on his own terms, Steve compares this to trying every ride at a local amusement park. At first, he says he was scared to take a ride, but once someone he “really trusted” told him “it was not scary,” he found the courage. Here, Steve emphasized the importance of having someone trusted with him. Steve thought this example was not very different from being in hospitals and having to “get stuff done to you, except that on rides you know that you can back out before you’re there.” In the hospital, Steve explained, you can’t do that. Sometimes Steve has found that, like at the theme park, the things he has to do at the hospital are not as frightening as he thought they would be, though he admitted that “sometimes they are worse.” Steve explained that at the hospital you have to go through procedures – you can’t back out. Steve explained that you definitely need courage to get through it. Here Steve vividly explicates what many pediatric patients describe as being “trapped” – they “can’t back out” of having procedures or taking medicines that make them sick in the short term, but which may help to make them well in the long term. Rather than use the language of feeling “trapped” or “out of control” or “forced,” Steve used an entirely different metaphor, recalling a "scary" ride at an amusement park, the importance of having someone with you who has been there and can tell you that it’s “not too scary,” and finding the courage in himself to get through it. He did not pretend that it was all fun, or even that there would necessarily be a happy ending (e.g., it could be “worse” than he imagined), but his view of this experience as somewhat of an adventure may help to keep up his spirit and his attitude.

When asked whether anything has changed since having cancer, Steve focused on
how he has changed physically. Steve explained that he is not as active as he was because
of how sick he has gotten. Steve agreed that it has been hard on him to become less
active. He was really active. He used to ride bikes all around the neighborhood with his
friends, and he can’t do that anymore. Steve said his friends can go faster and do not get
as tired as he does. “They’re just a lot better at sports” than Steve is now. Steve
identified (and continues to identify, as seen in his choice of pseudonym) with being an
active kid – an athlete like his father. That his illness and treatment have limited his
ability to be active and play sports has been a particularly difficult blow for Steve.

At one point in the interview, Steve imagines that he will be playing sports again
in the future. He continued, saying that he will play the same things that his dad has
played: basketball and football. When pressed, Steve said that he knows that in the
future it will be a lot harder on him to play sports, but that it is what he hopes he will be
doing. In this brief interaction, we again see Steve struggling to come to terms with the
news that the doctors will not likely be able to cure his cancer. His tumor forced him to
be less active. Chemotherapy and other treatments made him sick and tired. All of this
would be endurable except that he has been told that he has an inoperable tumor that has
not responded to treatment. Steve was left struggling to come to terms with what this
means for him. He had continued to imagine and hope for a future in which he would
again be able to be active, to participate in sports, and to lead a “normal” life. When
asked about the future, he immediately shared this vision he had had for himself – only
later did he stop to question whether that future remains a possibility for him.

Steve drew himself as a very small smiling figure with a cap covering his head and
one eye. This depiction of himself as small, almost overwhelmed by the paper, indicates
that Steve may be feeling small, threatened or overwhelmed (O’Brien and Patton, 1074;
Clatworthy et al., 1999). Indeed, all of the figures in Steve’s drawings are quite small, perhaps indicating all of their powerlessness to change what has happened to Steve. This would certainly make sense in light of the news he has received regarding his prognosis. When I asked him about the small figure, Steve agreed that he drew himself “pretty small.” He nodded his head and said that he knows “that is supposed to mean something,” but says that he just honestly sometimes draws himself small and sometimes draws himself big. “This one is just small.” I asked, but Steve couldn’t think of anything different about him or about how he is feeling when he draws himself big versus when he draws himself small. When pressed about how he felt then during the interview and while in the clinic for his treatment, Steve replied at first that he felt pretty good. Steve said that he does not like feeling sick from the chemo, but he explained that he was not yet feeling sick from his latest round of treatment. Finally, Steve added that he is nervous and thinking about when he will be sick.

For his second drawing, I asked Steve to draw himself in the clinic or hospital (Appendix C, Figure C2). As he began, Steve asked if he could just draw the outside. When I asked if he could draw himself inside, he responded by drawing the outside of the hospital, with himself just inside the doors in the foyer. He did not at first want to situate himself inside, and when pressed, drew himself just barely in the doors. He pointed out all the details he included (i.e., parking lot, driveway and parking attendant). Though he did include realistic details, he did not include in this drawing anything that would identify him as a patient. He drew himself in the happiest part of the hospital: stopping to watch the trains in the foyer as he is on his way out. Here he is leaving behind needles, painful procedures, and anything unpleasant or fearful about the hospital.

There is also something striking about Steve’s decision to have he and his mom
“on [their] way out” at night. This is not unrealistic, since he has in fact left the hospital late at night. However, the image of leaving the hospital and stepping out into the darkness with only the stars and moon to give light may stand as a symbol for Steve and his mother’s future of leaving the hospital and treatment behind and stepping out into a future that they can only dimly see or imagine. Steve said that he has fun looking at the model trains and the airplane that are displayed in the hospital foyer. Later, when I asked Steve to tell me about what he drew at the back of the plane, he laughed and said, “Yeah. The plane’s on fire.” When I asked about this, Steve laughed, shrugged his shoulders and agreed that this drawing looks like a happy scene until you notice that the plane is on fire. Steve agrees that this picture is similar to the story of his diagnosis: he was a happy, carefree, active boy while all the while the danger of the growing tumor was looming. Steve says that it is “kind of wacky” and “kind of scary.” Here he acknowledges the sense of doom and disaster the plane adds to his picture, but distances himself by laughing and calling it “wacky.”

This theme ran throughout Steve’s drawings. For example, Steve drew all of his figures (i.e., of himself, his mother, his family and friends) in these drawings very small. Even when Steve uses up the space of the paper with buildings and scenery, the figures themselves remain small. Drawing small figures or using very little of the space provided...
typically points to feelings of anxiety, insignificance, threat or loss (O’Brien & Patton, 1974; Clatworthy et al., 1999). Throughout the drawings we also see a constricted use of color (e.g., only one to four of the available eight colors used), which also tends to signify increased anxiety (Clatworthy, et al., 1999). Although we find these signs of intense anxiety, we also notice that Steve drew his figures smiling, one of the best indicators in human figure drawings of a positive feelings and a generally optimistic outlook (Machover, 1949; Burns & Kaufman, 1970). However, Clatworthy et al. (1999) have suggested that smiling in threatening positions may indicate a child’s attempt to deny or mask his or her true feelings (p. 15). In Steve’s case, perhaps his figures are smiling (and, for example, supporting him) in the face of the anxiety of Steve’s uncertain future.

Steve had asked if it was ok for him to outline the drawings first then fill them in with color. This may simply be the way Steve likes to draw, but in light of him coming to terms with new information about his diagnosis, it was interesting to see him sketch out the “big picture,” then go back to fill in the details and add just a few highlights of color. In children’s drawings, the use of color often indicates the ability to acknowledge and own the emotional connection to a given experience (O’Brien & Patton, 1974). Similarly, Clatworthy, Simon and Tiedeman describe hospitalized children who are feeling particularly anxious as apparently lacking the energy to choose more than one or two colors (Clatworthy, et al., 1999). Steve’s guarded use of color may be a measure of the guarded emotional response he felt, either in response to this new news about his prognosis, or in particular in discussing these issues with me. Steve’s use of color in only a few figures and objects in his drawings also serves to highlight them as particularly meaningful. For example, I might not have noticed right away that Steve had drawn the airplane in his second drawing “on fire” were it not for the fact that the blue plane with
red flame emerging from its engine was one of the only objects Steve chose to add color to in this drawing.

Steve told me that he has met many new friends at “cancer camp” and at the hospital. Steve reiterated that he likes “everyone” at the hospital. He said that he has made some of the best friends at the hospital, including the nurses. There is one nurse who is “like a best friend” to Steve. Steve said he “would never have met her if [he] hadn’t had cancer.” Though he feels nervous about coming to the hospital for treatment, he looks forward to seeing his friends. He may miss friends from school when he has to stay home, or the friends he used to be more active and play games with, but the new friends he has made at the hospital have become a new network of support.

Steve also talked about how his experience of living with cancer has given him the opportunity to help others. As a “cancer ambassador,” Steve gets to go to sporting events and to talk about cancer “so that other people will know about it.” Steve also wants to be a volunteer at the hospital and help kids out. He can understand what they’ve been through “because it happened to [him].” He recognizes that his experiences leave him uniquely qualified to help other children with cancer directly or by raising awareness and support for research. Indeed, his willingness to participate in this study is another way in which Steve lent his own experiences and expertise to help other children with cancer.

Steve talks through what he is drawing as he draws the worst thing about having cancer (Appendix C, Figure C3). He doesn’t really know what it looks like, but he tries to draw his tumor. Steve thinks that the worst thing about cancer is his tumor, both what and where it is. He says that he’ll make a big round shape the size of a grapefruit for the tumor. Interestingly, though he spoke of making a “big” life-size tumor, in the end he
decided to draw it quite small. Here again, this may reveal Steve’s desire to explain his experience and situation, yet keep his emotions in check by maintaining distance from the small (i.e., far away) image at the same time. Steve explains that the tumor is “the main thing that the doctors are trying to get rid of, and they say the worst thing is where this tumor is.” Steve’s heart is getting “squished.” Interestingly, throughout Steve’s drawings his figures are fairly still (e.g., standing, watching). The tumor in this drawing is described in much more active terms (i.e., “growing,” “wrapping around,” “squishing,” “choking.”) The tumor’s insidious growth has brought Steve’s activity, and that of his doctors, family and friends, to a near halt.

At first Steve explains that his tumor was no bigger than a quarter, but it has grown to the size of a grapefruit. Now, Steve explained, the tumor is wrapped around the aorta and blood veins that “feed the heart.” Steve knows that the aorta is a big part of the heart “that your body can’t live without.” The doctors can’t try to remove the tumor because it is too close to the heart. They are not going to attempt surgery on Steve because it is too risky. They have told Steve that he “would not live through it.” If they did, Steve would be “floating away” [die]. And if they don’t cut it and it keeps growing he will die. The “worst” thing he speaks of here is not the pain of procedures, or feeling
different from other children, but rather a profound realization that whether the doctors
do try to operate or if they do not, he will die. Steve chooses this anatomical drawing to
depict the profound and painful truth that he may be dying. Through this drawing, Steve
was likely seeking to explain his tumor to me as it was probably explained to him (e.g., in
technical terms, including visual graphics of the heart, etc.). Using an anatomical drawing
allowed Steve to be distanced from what he drew (e.g., “this is not me - this is a heart, an
objective thing over there). By drawing his “squished” heart, rather than a drawing of
himself dying or dead, Steve was able to maintain some distance from the full emotional
impact of his revelation. In this way, he could talk about dying, but look at it
physiologically, not personally.

Steve said that it might take a while to draw what helps him get through the tough
times (Appendix C, Figure C4). Steve drew his family and friends who help him “get
through everything,” especially his mom. After I commented that I thought at first he
was drawing angels, Steve said that is how he draws arms, but that “they definitely are
angels to [him].” Steve said that these people have helped him the most because they
really care: they talk to him about having cancer and tell him everything is going to be ok.
They are always beside him, and, Steve explained, “that is mainly what [he] needs.” Not
surprisingly, Steve focused on his close relationships with family and friends as a source
of strength and courage.

Throughout his drawings and the interview, Steve focused on his relationships
with others. He often spoke of the close relationship he has with his mother, his friends,
and the nurses and other patients at the hospital. Steve deeply values these people and
relationships in his life and finds that they are most important in helping him cope with
the trials of living with cancer.
Steve agrees that he likes to do things for people and help out. When asked to draw his family Steve asks if he has to draw them all again because it was kind of hard. Steve had already acknowledged the support of his extended family and friends in the last drawing. Here, he focused on his most immediate family, his mother (Appendix C, Figure C5). Given that his brothers are older and out of the house, and that his parents are divorced, this drawing is an accurate depiction of his immediate family. Here in his drawing, as probably in much of their lives together, Steve and his mother are on their own, in an empty theatre. Steve says he and his mom go to the movies to “get away from it all.” It is a good escape. Steve agrees that he and his mom, sometimes on their own, stick together to see each other through. Steve described his mom as nice, very silly, someone who likes to play around, and who is “very, very sensitive. Sad things and very nice things make her cry.” Steve explains that he and his mom like to do “everything” together. They ride bikes, walk together, and as he has drawn, see all kinds of movies together. Steve likes snuggling with his mom. They get under the covers and snuggle. Steve said that it is “comfy and comforting having her beside [him].” Steve shares a particularly close bond with his mother through the good and playful times and now through the tough times. He appreciates that they stick together, talk about his cancer when he needs to, and escape when he needs to. The bond of emotional and physical closeness shared by him and his mother has been a great comfort to him. He knows that his mother is both figuratively and literally beside him.
Narrative Analysis: Harry. I first met Harry and his mother in the outpatient clinic waiting room where Harry sat on a couch absorbed in his Game Boy. He was friendly and energetic, particularly when he learned that I was familiar with the game he was playing. He sat close to his mom, listened attentively and asked questions as I explained the study and went over consent forms with him and his mother. We had originally planned to conduct our interview later that day but his blood counts were too low to receive treatment. We rescheduled for the day of his next clinic appointment. That next time I met Harry he seemed less energetic than he had been during our first meeting. He sat quietly in a corner hunched over his game with a baseball cap pulled down low over his eyes. I learned from his mother that he was scheduled for a spinal tap later that morning.

Harry would turn nine years old the week following our interview. He had been diagnosed with leukemia seven months earlier. As we got down to work, Harry often seemed self-conscious about what and how he was drawing. He often downplayed his ability (i.e., “I’m not very good at drawing”) perhaps as a defense against anxiety or to diffuse any potential criticism from me. Before beginning the first drawing, Harry showed me a finger on his right hand that was bandaged from a blood draw and warned me that he would not be very good with a pen. On several occasions he claimed that completing a requested drawing would be “impossible.” He did, however, respond to encouragement by agreeing to continue with his drawing.

When asked how he would describe himself, Harry focused on his physical appearance saying that he has a little bit of fuzz on the head and hazel eyes. When asked to describe himself further, he added that he likes to play his Game Boy. Harry described

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1 Harry is a nine-year-old caucasian male diagnosed with leukemia. He chose “Harry Potter” as his pseudonym after the fictional boy wizard in his favorite series of books, movies, and video games.
himself as funny and demonstrated that he can do funny voices. He warned me, someone he had only recently met, that he is kind of shy when he doesn’t know somebody. However, once he gets to know someone he is not shy anymore.

Harry seemed to be particularly self-conscious about his hair loss, mentioning it several times, then both in person and in his drawing covering his head with a cap. In describing his experiences Harry also seemed somewhat guarded, preferring to keep a safe distance from any feelings of fear or anxiety associated with his treatment. This was evident in his frequent use of humor to diffuse otherwise anxious feelings (e.g., “I’m used to putting hair on people,” speaking in one of his “funny voices”). In describing his illness and treatment, he also frequently spoke in terms of “you” rather than “I” (e.g., “the chemo makes you tired”), disassociating himself with the experiences he was describing.

In discussing what it means to have cancer, Harry explained that when you have leukemia “you have to go on chemo treatment for a long time.” Harry’s description that to have cancer means to be on chemo indicates that his focus is squarely on treatment. He did not immediately describe the life-threatening nature of his illness, nor did he jump forward to being cured. After seven months, Harry had settled into the routine of treatment: he felt he had already been in treatment for a long time, and, since he had not yet experienced a remission, he may continue for “a long time” to come. Harry added that when you have cancer you “get a lot of presents.” In the midst of coping with the physical and emotional ramifications of his illness and treatment, Harry seemed to have enjoyed an outpouring of sympathy and gifts of support from those who care and were concerned for him. He continued, however, by saying that he thinks that getting presents is “kind of over” for him. Harry says that his mom has explained that after a while
people don’t send as much “stuff” as they did when they first learned of his diagnosis. Harry braces himself by agreeing, saying that he doesn’t think people will keep sending presents as much as before. This brief interaction again spoke to Harry’s having been and continuing to be in treatment “for a long time.” The newness of the experience, for himself and for others, has worn off. This may suggest that Harry’s ability to look for the positive in the face of continued challenges and anxiety (such as preparing for today’s spinal tap) may have been wearing thin as well. He may take the fact that others are no longer sending gifts to mean that they no longer care as much or continue to be there for him as they were in the beginning. Harry may find that he must recognize other sources of ongoing support to keep his spirits up through the treatment days that lie ahead. 

Harry’s struggle to maintain a positive outlook may have been situationally grounded as he faced our interview feeling hungry, fatigued, and nervously awaiting a painful procedure. 

Harry pointed to the physical changes he has undergone, taking off his hat to show me that when you are on chemo “you lose your hair.” He laughed as he began his first drawing (Appendix D, Figure 1a) and said that drawing a picture of himself would be kind of hard because he was “used to putting hair on people.” In his self portrait Harry, first drew his bald head with a few hairs than later self-consciously added a baseball hat to cover his head. When asked what was different about him before he had cancer, he eagerly turned this first picture over and began to draw a picture of how he “used to be” (Appendix D, Figure 1b). Harry said that before he had cancer he felt good – and was not so tired. It was this second picture that he seemed to more closely identify with, saying, “I like this one better.” Harry said that in the future he would like to be more like this second drawing – more like he was before he had cancer. This suggests
that Harry does not identify himself as he is now, a pediatric cancer patient, but with who he was and who he hopes he will be again.

All of the figures in Harry’s drawings that are associated with his present, having cancer and going through treatment, are depicted as narrow stick figures. These minimal representations may have been a sign of defensive reluctance to reveal too much to a relative stranger, or a representation of feelings of anxiety, weakness and exposure associated with his present condition (Clatworthy et al., 1999). Stick figures are exposed and vulnerable – without flesh or clothing – while at the same time their cartoonish representation bears less literal resemblance to the artist, thereby offering a safe distance from the “real me” or “real feelings.” The only figure Harry “fleshed out,” fully clothed and secure, given weight and substance, as it were, was his spontaneous drawing of himself before cancer. It is notable that he spent nearly twice as much time creating this portrait as on any other picture. His emphasis, detail, and remarks (“I like this one”) suggest a longing for the days before cancer, and in particular, for who he was, literally and figuratively, before his diagnosis.

Throughout the interview, Harry oscillated between the positive and negative aspects of his experience of living with cancer. In particular, he often began by downplaying the negative or traumatic aspects of his experience, as if to say “it’s no big deal.” As he continued to talk and think about it, however, he described more of his
negative experiences and feelings. For example, he began talking about chemotherapy, an aspect of treatment universally dreaded by young cancer patients, by saying that it “isn’t too bad.” However, he later went on to say that when he is on chemo he misses school, has pain in his legs, loses his appetite and feels tired. Later he described being in the hospital as a “treat” because he can watch cartoons. Watching cartoons may be a treat, but it would seem to be a rather thin silver lining to the cloud of being in the hospital. Harry gave the impression of trying to think of something positive to say, either to give himself something positive to focus on or to help distract him from being overwhelmed by all the negative aspects of his experience.

Harry explained that when he is on chemo he cannot go to school. He described being “in, out, in, out, in, out” of school. This description reveals the lack of routine in Harry’s life when he is on chemotherapy. He cannot get used to the routine of being in school or to the routine of being at home. He does not know what to expect from week to week: whether he will be in school all week or only for a few days. When he misses school he has to do “a lot of work” at home to keep up with his class. This leaves Harry on his own to learn new material at a time when he already feels sick and run down such that he cannot attend school. When Harry cannot go to school he misses the familiar routine and the guidance of his teacher while also being isolated from the company and support of his friends and classmates. Harry emphasized this last point, saying that when he misses school he does not get to see anyone else except at the clinic.

When asked to draw a picture of himself in the clinic or hospital, Harry first claimed that it would be “impossible” for him. He protested, saying that he was “not very good at drawing.” After some encouragement, however, Harry made a silly exasperated face, took the paper and began drawing. Harry drew himself outside of the
hospital (Appendix D, Figure 2). In this drawing, Harry and his mother are at a safe distance from surgeons, needles, painful procedures, and all the negative experiences Harry has come to associate with the hospital. He proudly pointed out all the details he had drawn including the “Children’s” logo on the building with its trademark red balloon and all six floors of the hospital. Harry spent a great deal of time in his drawing and description focused on the details of the hospital – the *exterior* of the hospital. While he did include a good bit of detail in his drawing, neither the drawing nor his description spoke to what happens *inside* the building he drew with such care. Harry’s emphasis on the exterior draws focus away from the often frightening and painful things *he* experiences while *inside*. Even outside, however, the small figures appear overshadowed by the imposing building, indicating that Harry may feel anxious or overwhelmed in the hospital environment (Clatworthy et al., 1999). The figures of Harry and his mother carry potential movement, they are “walking towards the doors in front.” Interestingly, Harry did not describe them on the way home, a drawing which would have conveyed a sense of relief that the procedures and treatments for the day were over. Instead, he said they are on the way in, anxiously entering into procedures and treatments that await them. This spoke to Harry’s state of mind during the interview, both anxiously anticipating the spinal tap later that day, and in the midst of a treatment course with more to come. In this drawing, the figures of him and his mother lack facial expressions, perhaps simply because they were drawn so small that there was no space left in which to draw their facial features. Even so, the image calls to mind being faceless, losing sense of self, or of covering over the negative emotional response he has to being in the hospital (Clatworthy et al., 1999). Such an interpretation is further supported by Harry’s more restricted use of color here, predominantly red and black, colors which often represent intense feelings.
of threat, fear, or anxiety (Clatworthy, et al., 1999). Additionally, Harry shaded the windows on the oncology floor – his floor – explaining that you can’t see in from the outside. Harry’s interest in these windows seemed to be a reflection of his own need for privacy regarding his own “inner” life, experiences and feelings.

Harry said that he does not like that the hospital “smells bad.” He described it as smelling like the alcohol pads they use when they give a shot. He also complained that it is very cold in the hospital. He explained that he does not like getting shots and procedures in the hospital or all the medicines he is given. Harry’s comments here point to the hospital being a cold, uncomfortable, unfamiliar, strange-smelling place. As soon as he enters the building, the smell reminds him of the shots, pain, and fatigue that accompany his treatments.

On the other hand, Harry said that he knows many of the nurses at the hospital now. He mentioned a few by name and said that he likes a lot of the nurses and thinks that they are really nice. He said that the nurses talk to him about “games and stuff.” Harry emphasized here that they are nice and talk about non-cancer-related things with him. In this way, the nice nurses may help Harry feel more comfortable and keep his mind on something he enjoys even while in the hospital or receiving treatment. It is also a way in which the nurses treat Harry as any normal boy his age, rather than as a cancer patient. Harry added that he has also gotten to know a lot of the doctors that are at the hospital and said that they are nice, too.

The third drawing in which Harry was to draw the “worst” thing about having cancer was the most direct call to describe and confront his own anxiety or fear and resulted in the most disturbed image in Harry’s drawings (Appendix D, Figure 3). For the worst thing about having cancer, Harry drew himself lying in bed receiving treatment
from and a large needle with “a lot of medicine in it.” In this picture Harry drew himself as a tiny figure lying in a bed – the most dependent passive position. The small figure may be overwhelmed by the environment, or is perhaps distant from the viewer, and the artist. The amorphous figure of Harry seemed to float over the bed, a posture indicating profound insecurity and feelings of being ungrounded (DiLeo, 1970; Clatworthy et al., 1999). In this drawing Harry is represented by an ambiguous body shape with little relation to the head, the only recognizable feature. Harry’s representation here bore little resemblance to the Harry before me or the Harry in his previous drawings, indicating Harry’s disassociation with the experience and associated feelings (this is barely even a person, definitely not me). Harry agreed that compared to the first two drawings it looks like he is “barely there” in this one. Harry said that he did not know what made him want to draw himself this way here. When asked how he feels when he is in the hospital and about to get a shot (as he has drawn in this picture), Harry said that he feels “scared.” In the picture, Harry is receiving medicine, though he is isolated with no one there to administer the medication or to be with and comfort him. The eyes Harry drew are tiny pinpoints looking out from a helpless and defenseless body which lacks arms or legs. The oversized needle draws attention as the object of primary concern in this drawing. In describing how he feels when getting treatment, Harry said that the
needle doesn’t actually hurt, rather it is “the medicine going in” that makes it hurt. Harry said that the medicine makes him better but it also hurts where he gets the shots in his leg. It hurts when the medicine is going in and afterwards. Despite the way he feels at the time he gets his treatments and afterwards, Harry reiterated that the shots “will make you feel better.” He understands that receiving these treatments, painful though they may be, are what may help him eventually feel better and potentially recover from his cancer.

Harry was also bothered by the fact that all the medicines make him “not want to eat” and that he is no longer allowed to eat some of his favorite foods—things he would want to eat if he was hungry. Harry relayed that his dad said sodium nitrate, found in some of his favorite foods, might have been one of the reasons that he “caught” leukemia. Harry’s understanding of the potential causes of cancer has a twofold effect. On the one hand, he may believe that if he can avoid these specific foods he may avoid worsening his condition now or avoid a relapse in the future. On the other hand, he may believe he did something to bring cancer upon himself by just being a normal kid, eating normal foods that he loved. This understanding could lead to increased vigilant behavior, particular in terms of what he does and does not (can and cannot) eat (Kister & Patterson, 1980; Perrin & Gerrity, 1981). It is interesting that Harry notes many times that he has no appetite while on chemo, a common side-effect, yet also potentially meaningful in light of this concern about eating cancer-causing foods.

Harry said that it was “easy” to draw what has helped him get through the tough times since he has had cancer. Harry drew his mother smiling and framed by a colorful rainbow (Appendix D, Figure 4). This is a striking contrast to the previous drawing. In the last picture, Harry drew himself as small, defenseless, expressionless figure receiving his chemo treatment. Here, he drew his mother as a tall smiling figure. Where Harry feels
small and weak, his mother stands strong and tall. At first, Harry could not tell me exactly what his mom does that has helped him. It seems that there is no one thing that she does that helps him, but rather all the little things – her presence and support throughout his illness and treatment – that have been a source of comfort and strength to Harry. Harry said that his mom reads to him and always comes with him to the hospital. Whenever Harry has to get a shot, he said that his mom squeezes his hand. He and his mom have a good time together. Harry made up a song for his mom and has funny names for her. He relayed that he calls his mom his “fuzzy pillow” because when he has his port accessed or a spinal tap his mom is his “pillow.” She sits on the table with her legs on both sides of him and holds him while Harry lays down on her. Harry’s use of all eight available colors in this drawing is a marked shift from the last picture in which he used only brown and black to depict the “worst” part of having cancer. The use of the full range of colors indicates that Harry connected here with a more full range of emotion, including optimism and happiness (Clatworthy et al., 1999). Indeed, in his descriptions, Harry described his mother as there to laugh and play with him during the good times and to literally wrap herself around him through the worst of his experiences. Harry is comforted by the close physical comfort and support his mom gives to him as well as by the emotional connection and sense of humor that they share. Symbolically depicted in this picture, Harry’s mom is the ray of light – the rainbow – shining through clouds and rain.

When asked to draw the final picture, Harry immediately said that it would be impossible to draw his family because he has “too much family.” He said that he would have to draw his cousins, his aunts and uncles “and everything.” This could be interpreted as Harry’s way of saying that he has so many people who support him in his
family that there are just too many to draw, or it could be an anxious or defensive gesture of refusing to let me in to view his family, or simply a sign of his fatigue at the end of the interview. In the end, Harry agreed to draw just his immediate family: himself, his sister, his mom and his dad (Appendix D, Figure 5). When reminded that everyone in the drawing should be doing something, Harry again objected and asked if he could “please just draw [his] family.” After much continued encouragement, Harry drew his family “standing around” for a family photo. Here the family is standing in a static pose for a family picture. They might later enjoy having a picture of the family, but here, as they are drawn, they do not enjoy having the photo taken.

Harry has drawn his family not in their relaxed natural positions or relationships, but frozen in a somewhat uncomfortable moment in time. Only once the picture has been taken can they relax and resume their normal activities and life. Harry said that his mom is not smiling in the drawing because “she doesn’t like to take pictures” (as it would seem Harry does not like to draw this one!). When asked what he could tell me about his family, Harry picked up the tape recorder and said loudly that he had “no idea” what else to say about his family. Given that Harry previously went into great detail describing his mother and their relationship, his resistance and lack of detail here could well indicate that Harry was feeling distant from or less supported by his sister and father. The only concrete information he revealed about the relationships in his family was that he likes to play golf with his dad. This speaks to a normal father-son (non-treatment-related) activity. In this drawing Harry’s father is the most physically distant from him. This may reflect a strained relationship, or relatively less contact as their interactions may have changed now that Harry is sick and may not be up to many of the physical activities, including golf, which they previously enjoyed together. Even so, Harry drew the whole
family physically close, indicating that he has a generally good sense of family cohesion (O’Brien & Patton, 1974). Notably, his mother and father are close suggesting that Harry sees them as standing together through this difficult (or here in this drawing, uncomfortable) time. This family picture may be a useful metaphor for the interruption in their lives that Harry’s cancer and treatment has been. It is not something they enjoy, but they will stand together to get through it. Harry did say that having cancer has brought his family closer together.

Particularly in his final two drawings, Harry omitted hands and feet from his drawings. These types of omissions generally speak to a child’s concern about their ability to interact with the world and sense of being ungrounded and, are more frequently omitted by anxious and insecure children (Clatworthy et al., 1999; DiLeo, 1970). As I mentioned, this interpretation did indeed seem to apply to Harry’s third drawing of the “worst” part of having cancer in which he is anxious, frightened and helpless. These last two drawings, however, seem more to be “sketches” than detailed representations of his experience. Harry drew here only what he had to to get his meaning across. His energies seem to have been tied up in his concern for the upcoming procedure. Taken in context then, his omissions seem more directly related to Harry being quick and careless while anxiously awaiting his spinal tap than to any more global concerns that I witnessed during our interview regarding interaction and grounding.

Towards the end of the interview, as the time for his spinal tap drew nearer, Harry seemed to grow more fatigued, distracted, withdrawn and even resistant. Whereas he answered questions and elaborated more easily at the start of the interview, by the end he did not want to draw the last picture as directed, then after being asked to describe the drawing shrugged his shoulders, and even picked up my tape recorder to say loudly into it
“I have no idea.” This was a marked shift in Harry from his behavior in our first meeting, and even from his behavior at the beginning of this interview. This resistance could have been the result of the general anxiety and guardedness Harry feels in the face of living with cancer, or from discussing his experiences of illness and treatment with someone he did not know well (he admitted that he is shy around those he does not know well), but seemed most likely to be a response to the growing dread he felt towards the impending spinal tap. No matter how well he might have generally been coping, this was certainly a time in which he could be expected to be anxiously dreading the painful procedure and withdrawing into familiar coping patterns.

Throughout the interview, Harry attempted to distance himself from thoughts about his illness, especially about procedures. He downplayed the negative aspects of treatment (pain, fasting before procedures, feeling tired), he made jokes, laughed and tried to connect with me about topics outside the interview (his favorite book or video game). He also spent a significant period of time talking about his mother, the funny nicknames he has for her, and the song he made up for her. These all seem to point to strategies Harry might normally employ to help him cope (through distraction, or comfort) with “the worst” part of living with cancer: painful procedures, such as the scheduled spinal tap. Ordinarily he might have turned to his game boy or talked to the nice nurses to help distract him, or joked around and snuggled with his mom while preparing himself for a spinal tap. Continuing the interview with me where he was repeatedly asked to dwell with his experiences and feelings about living with cancer may have in effect separated him from his normal methods of coping and otherwise preparing for a spinal tap. As Harry grew more anxious, he became more distracted and dismissive of the tasks and questions that I asked of him during the interview as he girded himself for the upcoming
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procedure.
**Narrative Analysis: Crystal.** I met Crystal and her mother in the waiting room of the clinic before Crystal’s scheduled treatment. Crystal smiled quietly as I introduced myself. As I reviewed the consent and assent forms with Crystal and her mother, Crystal waved to other kids in the clinic, some of whom came over to talk with her. Her mother also knew and spoke with other parents who passed through the clinic that morning. As we left her mom in the waiting room, Crystal seemed to be in good spirits, though she limped and winced slightly as she walked with the help of a cane.

I caught my first glimpse of Crystal’s friendly, energetic and sweet personality in her bright color-coordinated outfit, rhinestone butterfly earrings, and beret. Her beret, both in person and in her drawings, in particular struck me as a positive, stylish means of coping with any self-consciousness she might feel about losing her hair and looking different. Her positive and energetic personality was reflected in her self portrait (Appendix E, Figure 1) and throughout her drawings, particularly in the wide range of bright colors Crystal chose in drawing herself, others, and various scenes both in and out of the hospital (O’Brien & Patton, 1974; Clatworthy et al., 1999). The human figures in her drawings, including her representations of herself, are somewhat small for the size of paper she was given to work with. This may reflect Crystal’s feeling anxious or cautious in a general sense in the face of her illness, or specifically in the context of waiting for a treatment (scheduled later that morning) or in meeting with me for the first time (O’Brien & Patton, 1974; Handler & Habenicht, 1994; Clatworthy et al., 1999). She also tended to draw herself and often others with large eyes. Such wide-eyed figures may represent a feeling of vigilance or cautious watchfulness, again in relation to her general situation or in response to specific situational factors (Clatworthy et al., 1999). Crystal generally drew

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4 Crystal is a ten-year-old Hispanic female diagnosed with leukemia. She chose “Crystal,” her “favorite name,” as her pseudonym.
herself and other figures smiling, reflecting her own positive outlook (Burns & Kaufman, 1972; Clatworthy et al., 1999). Her representation of herself as smiling in the clinic could be interpreted as a defense against the fear and anxiety she might normally experience at the hospital, yet Crystal was able to depict herself as sad, crying and in pain when drawing “the worst” part of having cancer. This suggests that Crystal does indeed allow herself to feel and own more negative feelings while maintaining an overall positive outlook.

The people in Crystal’s drawings are shown interacting at a physical level, engaged in common activities (e.g., playing frisbee), and at an emotional level (e.g., nurses who are sad that Crystal is sad, mother who is happy that she is happy). Frequently in her drawings others attend to and look at her while she looks forward in a more independent posture. These figures are usually grouped closely with few barriers between them. All of this suggests that Crystal relates well with others in her world (Levenberg, 1975; O’Brien & Patton, 1974). The level of emotional connectedness depicted in her drawings particularly stood out as a sign that Crystal feels these others relate to, care about, and are sympathetic to her feelings.

Crystal described how her knowledge of her diagnosis and prognosis has developed over time. When she was first diagnosed, Crystal did not know what it meant to have cancer. Crystal thought that cancer, like a cold, would take a couple of days to get over. She was told instead that she would be in treatment for “a couple of years” (a standard treatment cycle for acute lymphoblastic leukemia, or ALL). Crystal has kept her eye on this goal, repeatedly referring during the interview to her treatment ending and her cancer being “cured” in two years. She also referred to the other children in the clinic as coming to be cured, perhaps without the recognition that not everyone may have an
As she looks ahead to the day when her treatment will end, Crystal also focused on the positive experiences she has had along the way. Crystal explained that she has to take her medicine, but she also gets to do fun and special things at the hospital where she gets her treatment. She gets a toy from the prize closet when she is done with her treatment. She can also do “fun stuff” like go to camp with other children from the hospital. Crystal met many other kids with cancer during her week at camp this summer. Crystal clearly enjoyed her experience. She smiled broadly as she described riding down the zip line, a physical feat she was proud to have accomplished even while sick. She went on to describe the everyday activities around the camp: swimming, camping, eating meals, going to meetings. These normal camp activities and their importance to Crystal remind us that at camp she is allowed “normal” experiences. In the environment of the camp where all the children were also living with cancer Crystal was just a “normal” kid. She mentions other ordinary activities, like being with her friends at school, swimming, watching movies, and playing video games that also allow her to be “regular” and to “forget” about having cancer. Crystal said that being able to feel like a regular kid again helps to get her through her illness. “Forgetting” and being just a “normal” kid, allow Crystal to distance herself from being a cancer patient. Throughout her self description Crystal does *not* identify herself as a cancer patient. Instead, she simply described a “normal” friendly 10-year-old girl. She worries about upcoming procedures, but out of the hospital she has tried to keep up a normal routine and relationships.

Reflecting on how she has changed since having cancer, Crystal focused on the immediate physical changes. She said that before she had cancer her legs were stronger, she wasn’t sick that much, and she had longer hair. Crystal said that it is hard to be sick.
Since she has had cancer Crystal worries more. She finds herself worrying about the painful treatments and the hospital. Coping with the pain from her treatments and bone pain from the cancer itself has been one of the greatest challenges for Crystal. When she is sick and in pain she finds that there are many things she cannot do for herself. At times she has been unable to even walk on her own and has had to be carried. When she is sick she also misses going to school, being with her friends and engaging in activities that she enjoys. Having cancer has imposed some limits on her independence and her possibilities. This loss or limitation of independence has not left Crystal bitter or passively accepting her situation. Her drawings include others taking care of and supporting her, but she does not resign herself to bed, the most passive position depicted by children in hospital. She is standing, upright and independent, without the support of a cane, in all of her drawings but those in the clinic, where she sits for the doctor during her checkup and treatment. Here she has somewhat adopted the posture of the patient, children in the clinic do indeed sit on the examining room beds during examinations, but Crystal never depicts herself as passively “taking it” lying down (Clatworthy et al., 1999). From both her drawings and her self-description it is clear that Crystal does not identify herself as a cancer patient, but rather as a regular kid who will one day soon complete her treatments and return to all of her regular activities and life. This is a reasonable expectation given the information she has been given regarding the treatment course, high remission and cure rate for her type of cancer (ALL) as well as the fact that this is her first treatment course, being diagnosed only nine months previously. Crystal has not experienced a cycle of remission and relapse that would give her and her doctors greater cause for alarm. Interestingly, however, Crystal never mentions or worries aloud to me that her treatment might not be successful even though she knows other children through the clinic and camp who have
not been as fortunate. Again, this could be due to her optimistic attitude, an attempt to mask the anxiety that such an admission would allow, or an attempt to distance herself from such painful and anxiety-producing thoughts with me, a relative stranger. Later, Crystal drew her family in the future, rather than the present, perhaps imagining a happier time when her treatments will be over instead of thinking of her family now in the midst of living with her illness (Appendix E, Figure 5). In this picture she gave herself long hair and is no longer covering her head with a hat. In the future she hopes her long hair will grow back. In the future, as in her drawing, she imagines being done with her treatments and being able to get back to all the things she likes to do. In this way she imagines her future as like her past, a time when she was a carefree “regular” kid.

Crystal’s description and drawing of the clinic began to reveal her ambivalence about being there (Appendix E, Figure 2). Crystal said that it is “boring” in the clinic, but you can watch tv there. It is noteworthy that she spoke of the clinic as boring, rather than as a frightening place. In this description she distanced herself from the frightening and painful procedures that she described undergoing in that environment. She was probably responding in part to the long periods of waiting in the clinic before her appointment as well as to the fact that in almost a year she has grown accustomed to the routine at the clinic. Crystal does not like it in the clinic when they give her medicines in a “leg shot” or a bone marrow aspiration or biopsy because it hurts. These painful procedures are what she described as the “worst” part of having cancer. At the same time, she knows the treatments are going to help her get better.

For her clinic picture, Crystal drew the doctor giving her a check up. She said that she likes her doctor (Appendix E, Figure 2). In the drawing, the doctor is going to take her temperature, ask her how she’s feeling and look at her blood counts. In this drawing
there are no invasive procedures or needles. Crystal chooses bright colors and wall hangings to decorate the examination room. In this drawing both Crystal and her doctor are smiling. This depiction may in part serve to mask the anxiety Crystal feels on less mundane trips to the hospital (Clatworthy et al., 1999). This image distances Crystal from the negative experiences associated with her treatment while reflecting Crystal’s real positive feelings towards the doctor, arms outstretched, who cares for her. Similarly, though the nurses administering her treatment in the next picture are frowning, Crystal explained that they are not mean or frightening – the nurses just don’t like her to cry. When she finally finishes her treatment it is the nurses who take her to the prize closet to pick out a toy. In both of these descriptions, Crystal spoke positively about her doctor and nurses. These are the very people who administer the painful procedures Crystal dreads: the shots, blood draws, and bone marrow aspirations. Yet, she emphasized that she likes them. They are one of the positive aspects of the clinic experience for her. Crystal understands that these people do not want her to cry or be in pain, and that they are there to care for her and help her get better. Many of Crystal’s drawings and descriptions involve this focus on relationships and being attended to by others. Others, be they her nurses, doctor or mother, are happy
with Crystal or sad with Crystal. They are there to support and sympathize with her through good times and bad.

Crystal laughed nervously while drawing a picture of the worst thing about having cancer. In this drawing Crystal is getting shots in her legs (Appendix E, Figure 3). In contrast to her happy peaceful clinic picture, no one in this picture is smiling while she gets her shots, revealing a frank portrayal of this traumatic experience. Even in this depiction of one of her “worst” experiences Crystal’s wide range of color and expression of emotion (i.e., streaming tears and mouth crying out in pain) show that she is able to express and own the negative as well as the more positive experiences associated with her illness (O’Brien & Patton, 1974; Clatworthy et al., 1999). Getting “leg shots” is awful, Crystal said. In her drawing, Crystal sits on a large bed while two nurses with oversized needles administer her treatments. The large bed and needles are ominous reminders of the anxiety and pain Crystal feels during her treatments. What is of greatest concern in this drawing is the immediate pain of getting these shots. Crystal may feel sick and sore afterwards, but actually getting the shots is the worst part of the experience for her. This seemed consistent with her overall positive attitude: once she makes it through getting the shots the worst is over. In this drawing Crystal adopted a more passive posture, “being stuck,” literally by needles, and figuratively between the nurses with nowhere to go – no other way out. Crystal said she would tell someone else who just learned they have cancer that “you have all these treatments and you take all this medicine. If you don’t take your medicine then you’ll get more sick.” Though she dreads the pain associated with her treatments, Crystal also understands that her cancer is serious and that she would get sicker without them. Her focus on the future (i.e., in the short term getting through the shots, or in the long term being cured) helps Crystal endure
the pain of the present.

Crystal’s was a particularly interesting interview because she was called away by her nurse to endure what she had drawn and spoken of as the “worst” part of having cancer – getting “leg shots.” This occurred right after she had drawn her “worst” picture, during which she giggled nervously, and as she was beginning the drawing of what gets her through the tough times (such as getting her treatment). Although much of the interview took place with Crystal waiting to go for her treatment, she did not appear overly anxious, frightened or withdrawn. When she returned from her treatment, her sniffling belied the fact that she had been crying. Though she had clearly just endured a traumatic experience, she smiled at me and immediately picked up her crayon and resumed drawing where she had left off. Crystal’s ability to leave the fear and pain associated with receiving treatments and to get on with the task at hand was striking. It spoke, perhaps to her having learned through experience that the procedures are painful but that pain does not go on indefinitely. She is able to pull herself together and go on with her life, at least until her next treatment. Such traumatic events are a part of everyday life and become, though still traumatic, almost routine as they are endured by children like Crystal.

In the next drawing Crystal drew what helps her get through the tough times (Appendix E, Figure 4). In this drawing Crystal is done with her treatment and now has a toy from the prize closet to show to her mom. Again, she uses a full range of color and both she and her mother are smiling. Crystal said that her mom has helped her by talking to her about having cancer. She helps, particularly, by telling Crystal that she’ll finish all her treatments in two years. In this drawing her mother smiles and reaches out to Crystal. Crystal described how the nurses take her to the prize closet to pick out a prize when she finishes her treatment. Crystal said that during a treatment she focuses on
getting a toy when it’s over. Interestingly, Crystal chose to draw her stuffed animal in red, perhaps as a symbol for the blood and shots just endured. She said that it makes her happy to get a stuffed animal or other toy. In this picture Crystal shows off her prize to her mother who she said is happy for her. Both the nurses who take her to get a prize and her mother who happily acknowledges it recognize that Crystal has done something difficult — she has endured a painful and frightening procedure. Crystal takes up the clinic terminology of the “prize closet” and refers often to the “prize” she receives after her treatment. She has *earned* a prize, a stuffed animal purple heart, as it were, for enduring the painful treatments. Whether staying focused on the toy at the end of a specific treatment or the end of her treatments in two years, keeping the end in mind has helped to keep Crystal’s spirits up.

In her final drawing, Crystal drew herself with her parents and cousins. She and an older cousin are playing catch with a frisbee while her mom and dad are pushing her younger cousins on the swing set (Appendix E, Figure 5). This drawing depicts both Crystal’s immediate family as well as her cohesive extended family all of whom have supported her through her diagnosis and treatment. This drawing depicts a playful, happy, carefree scene. Unlike her other drawings, this one is grounded and extends the
full width of the page. She said that this drawing takes place in the future. The fact that
this scene takes place in the distant future may explain why the figures are well
proportioned, but slightly smaller (e.g., further away) than in her other drawings. Both
Crystal’s cousins and space separate her from her parents. Crystal is immediately facing
her cousin, but she can see everyone and her mom can see her. Here eye contact at a
minimum keeps Crystal connected to her mother. Crystal usually feels pretty close to
her mom and dad even though in this picture she is apart from them and they are occupied
with her little cousins. Ordinarily this sort of linear distance between figures, particularly
in a family drawing, would be attributed to feelings of emotional distance from others
(O’Brien & Patton, 1974; Brannigan, Schofield & Holtz, 1982). For Crystal, this may
reflect a move away from the dependence upon her parents she has experienced through
childhood, which has naturally been amplified by her illness, and a movement towards
independence and friendship outside her immediate family circle. We can anticipate that
this shift in focus will become more and more important to Crystal and more pronounced
both as she becomes physically stronger and as she edges closer to adolescence. Crystal
still drew her parents in a caring stance, only now their care is focused not exclusively on
Crystal and her illness, but on others, in this case Crystal’s younger cousins. Crystal
thinks this drawing may be set in the future. As in this drawing, once she is done with
her treatments Crystal will be able to get back to all the things she likes to do. When she
isn’t sick anymore, she imagines having the freedom to go off and pursue her own
friendships and interests while her parents will be free to pursue theirs.
This comparative analysis addresses themes that emerged across participants. Looking to these shared themes, may allow us to come to a deeper understanding of these children’s experience of living with cancer. However, it is equally informative to appreciate how these five different individuals, with different backgrounds, personalities, diagnoses and prognoses co-constituted and lived out these experiences. As health professionals, it is important for us to recognize individuals’ common and unique experiences, their strengths and their weaknesses in tailoring the information we provide, interventions and recommendations to best suit the individual.

*Changing Understanding of Self*

“I’m still me.” The first drawing the participants were asked to complete was a drawing of themselves. This drawing was followed up with questions about how they would describe themselves, how they would describe themselves before they had cancer, and how they imagine themselves in the future. I was particularly interested to learn how “having cancer” was integrated into these children’s drawings and self descriptions – in the ways they identify themselves and show or describe themselves to others. However, for these participants the fact that they had cancer (e.g., their physical condition, side effects of their cancer and treatment, etc.) was not immediately focal in their self-portraits and descriptions. Even in the face of the many changes and challenges they faced, the children in this study continued in many ways to see themselves and live their lives as they had before their diagnosis. In their self-descriptions they did not refer to themselves as “sick,” “different,” or even as “patients.” They spoke of being “regular kids” pursuing “normal” activities and interests, many of which they continue to maintain in spite of
their illness. For Alexis, these activities included drawing, biking, swimming, and playing with dolls. Junie described herself as someone who enjoys reading, singing, and playing with her pets. Steve mentioned that he enjoys biking, rollerblading, walking, and playing sports. Harry said he likes to play his Game Boy and practice his “funny voices.” Crystal, having at times been so weak that she had to be carried, appreciated being involved in ordinary activities at camp. Their continued focus on these “ordinary” childhood activities points to these children’s desire to maintain continuity between their life before cancer and the future they hope to continue into after cancer. It also seems to point to their appreciation for ordinary activities and the comforting routine of a “normal” day amidst so much change and uncertainty. Finally, at the hospital, clinic, or camp, these children are among other children who have cancer just like them. There they are “normal” and do not have to worry about anyone asking about why they have a bald head, if they are contagious, or any one of a number of questions. They all seemed to appreciate this opportunity to just be a kid, and not to be singled out because of their “illness.” This desire to be “normal” – not different, again points to their desire to maintain continuity between their life before cancer, life during treatment, and the future they imagine for themselves.

Distancing. Having designed the questions and interviews to include the child’s drawing, not just of “a person” in the hospital, but of themselves in that context, I was surprised by Steve and Harry’s drawings in which they themselves were not in the hospital at all, but rather outside of the hospital. Outside of the hospital, they are at a safe distance from surgeons, needles, and anything negative they may associate with the hospital. Similarly, Alexis’ narrow overhead view of our table in the clinic was indeed in the clinic, but was drawn from such an angle that none of the rest of the clinic
(examination rooms, treatment rooms, medical staff, medical instruments) could be seen. Both Junie and Crystal drew themselves in examination rooms, but they did not include anything (e.g., needles, or other medical equipment) associated with what they do, or more precisely, what is done to them, in those rooms. Several of the participants demonstrated a keen ability to focus on the present moment or something concrete (i.e., getting a toy after a procedure) that drew their focus away from worrying or being frightened about an upcoming clinic visit or procedure. In effect, each of the children distanced themselves in their drawings from the immediate environment and procedures of the hospital. This allowed them to draw more or less what was requested without becoming overly anxious. They did not like to draw themselves or think about being in the clinic or hospital until they had to. So they drew themselves, just as they had described themselves, outside of the medical world, or at least distanced from of the negative experiences of the hospital. Indeed, rather than drawing or discussing treatment and procedures that they undergo at the hospital, many participants instead chose to focus on the people they see and interactions with others that they have at the hospital. For example, Alexis, Junie, Harry and Crystal all spoke of the nurses and staff in the clinic, emphasizing how much they like them and that they are “really nice.” Junie and Harry described what they do with their mothers while at the hospital. Steve talked about actually looking forward to a visit to the clinic as an opportunity to see the friends he has made there. Their emphasis here on these interactions serves to keep focus on the positive aspects of the hospital – thinking about the hospital without thinking of the negative experiences they associate with being there.

This distancing was also reflected in participants’ tendency to draw figures in the hospital somewhat smaller (farther away). In Harry and Steve’s cases, the figures they
drew (Harry’s figure of himself and Steve’s diagram of his heart), did not resemble themselves in the way that previous drawings of themselves had. This dissimilarity served to distance them even further by making it look like “someone,” or “a heart,” but not necessarily Harry or Steve. I also noted throughout the interviews a tendency for participants to speak of what happens to “you” in the hospital instead of what happens to “me.” For example, Steve said that in the hospital “you get stuff done to you.,” Harry said that, “the chemo makes you tired,” and Crystal explained, “you have all these treatments and you take all this medicine. If you don’t take your medicine then you’ll get more sick.” The participants’ choice of language here again serves to distance them from painful procedures and traumatic experiences even while they were trying to describe them for me.

Finally, in the immediate context of the interview, Alexis, Harry and Steve all used humor to distance themselves or diffuse an anxious or fearful situation (or memory). Alexis’ giggled and whimpered as she drew the “worst” thing about having cancer, making the event seem more silly than “scary.” Harry spoke in one of his “funny voices” when answering difficult questions. Steve laughed when I noticed the flames in his airplane scene, and even after agreeing that it mirrored his own story, he laughed and called it “wacky.” Similarly, Alexis’ reference to her cancer as “the horror” helped to distance herself from what could be overwhelming emotions associated with speaking about “cancer.” Alexis’ speaking of “the horror” acknowledges the seriousness and terrifying reality of her diagnosis, but does so in a way that makes Alexis and others laugh.

Children in Their Role as Patient

Physical Changes. The one true reference in their self-portrait drawings to being sick was the fact that all the participants drew themselves either with very short hair or
with no hair at all. This acknowledged the hair loss they had each experienced with their chemotherapy treatments. After drawing their exposed heads, Steve, Harry and Crystal chose to cover their hair loss by drawing hats on their heads. They responded self-consciously to the fact that in changing their physical appearance, having cancer has also changed what others see when they look at them, and what they see when they look at themselves.

Later, when participants were asked about what has changed since their diagnosis, they focused on specific physical changes. For their self-portraits, Harry and Steve both spontaneously drew pictures of themselves before having cancer. This would appear to point to their identifying more closely with who they were before they had cancer, and perhaps a desire to return to that carefree life. They each described themselves as active (which requires being physically fit and strong, not weak, nauseous, or out of energy). Crystal described herself as being weak and having almost constant pain in her legs since she has had cancer. Junie said that before she had cancer she didn’t have so many bruises. Alexis said that when she was not sick, she ate “a lot.” These physical symptoms and side effects of their illness and treatment have altered the world of these children, at least temporarily, by hindering their ability to engage in many of the activities they enjoyed before their diagnosis. Despite the desire to maintain their “normal” life, these physical changes are a constant reminder that they live in the shadow of illness.

_Posture of the patient._ During the progression of drawings from self portrait to self in the hospital to the “worst” part of having cancer (which was generally represented as happening in the hospital), there was a corresponding progression in the way the participants’ drew their body position. Typically, the self-portrait involved standing, a more independent posture. With the second drawing of self in the hospital or clinic,
Alexis, Junie and Crystal depicted themselves seated. (The boys remained standing, but they were also outside of the hospital in their drawings.) Finally, during the “worst” part of having cancer drawing, Junie and Harry are lying down to receive treatment. This move from standing to lying down, reflects the posture these children assume (and are expected to assume) while they are in the hospital. It is a posture that allows the medical staff the easiest access to administering medications and treating the child. This change in position and perspective also reflects the participants’ feeling ill, exhausted and in need of rest, as well as a move from more independent to more dependent position – an active to a passive stance – in relationship to their parents and the medical staff who care for them.

The hospital environment. The participants described the hospital environment as being cold, “gross” smelling, with “bad” food and uncomfortable beds and pillows. Hospital beds, needles and equipment were drawn oversized, identifying them as ominous reminders of the pain, fear, and anxiety they represent in the imagination of these children. The children view the hospital as a strange, lonely, foreboding place. Being in the hospital, particularly as an in-patient, separates these children from the familiar and comforting sights, smells, sounds and even tastes of home. Although they described having some visitors and interacting with others in the hospital playrooms, they still miss regular interaction with classmates and friends.

Painful procedures. Each of the children described in some detail the painful procedures they have undergone in the course of their treatment. They described feeling nervous and frightened in anticipation of the pain of being “poked” by needles for blood draws, intravenous lines, and chemotherapy treatment. Crystal depicted herself crying out with tears streaming from her eyes as she received her treatment. Alexis’ first word to describe how she felt in the hospital was “screamy … They push [the needle] in and
out and in and out. It hurts.” Crystal, Steve, Alexis, and Harry also complained feeling
tired, sick, or losing their appetite after receiving their treatment. Though the children are
given anesthesia to help them sleep during painful bone marrow aspirations and biopsies,
the intense anxiety and fear they felt prior to the procedure, the pain they felt as it began,
and the residual pain they felt afterwards, made it one of the most traumatic experiences
that Junie, Crystal and Harry described.

Although they dread the needles used to administer these treatments and their side
effects, these participants were able to in one way or another, as Steve said, “find the
courage” to cope with these feelings. This seems to be due, at least in part, to the fact
that they understand that these medicines are “what make you well.” As Crystal says
plainly, “If you don’t take your medicine then you’ll get more sick.” These children can
endure the anxiety, fear and pain as long as they know it is in service of a greater good,
that is, they suffer the side effects of chemotherapy so that they might someday be well.

*Uncertainty.* Uncertainty entered these children’s lives with the diagnosis of
cancer. They wondered what cancer was. Was it like having a cold, as Crystal wondered?
This uncertainty became a constant companion as they nervously awaited the outcome of
tests, treatment, and ultimately, waited to see what their uncertain future would hold.
The hope to find a future in which they would again be well remained with all the children
with the exception of Steve, who had recently learned that treatment had not slowed the
progression of his tumor. Steve’s drawing of himself on the way out of the hospital,
stopping to enjoy the trains in the lobby, while the airplane blazes above, reflects the
looming danger and uncertain future that potentially exists for all of the participants.
While others have not received the poor prognosis that Steve has been given, the
possibility lingers that they may not be cured or may not remain in remission. In this
respect, all of the participants showed at least some measure (e.g., small figures, constricted color choice, etc.) of anxiety in the face of the treatment they are receiving. Steve’s story is a reminder that they may be only a step away from greater uncertainty and anxiety if treatments prove unsuccessful. As children slowly comes to their own understanding of what it means for them personally to be sick, they observe others’ reactions to their diagnosis and treatment. They are also in contact at the hospital, the clinic, and through camps with other children with cancer who are very ill and who die – an experience that brings home seriousness of their illness, even as they do not give up hope for a cure.

Dying. Only one of the participants in this study, Steve, spoke directly about dying. He had only recently been informed that his tumor was inoperable and that the treatments did not seem to have been successful. As he was coming to terms with being told there was virtually nothing else to be done, he alternated between a “normal” mindset – talking of playing football in the fall – and coming to terms with the fact that that “normal” future was slipping away from him. None of the other children specifically mentioned the possibility or a fear of dying themselves, likely in part because they were all still considered to be in “active” treatment, that is, their doctors still felt that the benefits, including the possibility for a complete remission, outweighed the risks and side effects of continuing treatment. Steve, meanwhile, was struggling to come to terms with his situation: he would die with out an operation to remove his tumor and that, given the location of the tumor, he would not survive such an operation. For Steve, this was the worst part of having cancer. As Steve was coming to terms with being told there was virtually nothing else to be done, he alternated between a “normal” mindset – talking of playing football in the fall – and coming to terms with the fact that that “normal” future
he had hoped for was slipping away from him.

Though the other participants might indeed have had fears or worries about the possibility of dying, such fears did not appear to be in the forefront of their minds. Their concern was focused on being in the hospital, receiving treatments, and suffering the side effects of those treatments.

*Resources Children Perceive as Most Valuable*

The drawings and responses about what helps to get participants through the “tough times” reflected the specific event or fear they described coping with. Those who described how they cope with “having cancer” in a more general way, described the importance of having the support, love, and care of family and friends. Those who described a specific “tough” experience, such as having an operation, tended to describe more concrete resources such as holding on to their mother’s hand or focusing on getting a toy after the procedure. All of these participants seemed to have found a combination of a support network and concrete coping behaviors useful to them depending on the situation.

*Rewards.* Both Crystal and Alexis spoke of being able to focus on something else, either momentarily thinking of playing with a toy or narrowly focusing on one day, or even one moment, at a time. They knew that when they were thinking about an upcoming procedure that they became nervous and frightened in anticipation. They found that by, for example, focusing with all their might on getting a new toy during the anxious time leading up to a procedure or during the procedure itself, they were able to get through anxiety-provoking and frightening experiences. For both of these girls, it seemed at first that just the reward, or “bribe,” of getting a toy was enough to get them through a painful and frightening procedure. However, upon further questioning, Crystal spoke of
earning a “prize” from the prize closet. The “prize” signified more than just a fun new toy to play with. The “prize” signified having won something or accomplished something great. For Crystal, the prize was a symbol of the nurses’ and her mother’s acknowledgment that she made it through a painful procedure. Alexis said that because her parents “love her,” they let her pick out a toy after she has had a shot or a scan. Here again, in addition to helping distract her from the procedure, the toy was a token of her parent’s love, an acknowledgment that she made it through the experience and a form of attention that made Alexis feel “special.”

Supportive relationships. Junie, Steve, Harry and Crystal all described a special person or person who helps them “get through the tough times.” Their relationships with these special others all involve the other (most often for these participants, their mothers) “being there” for them. This meant not only that the children felt figuratively supported, but also that they felt physically supported by them as well. For example, Harry described how his mother helps him get through a bone marrow aspiration by saying that she is always there for him, and is his “fuzzy pillow,” lying down behind Harry so that he can literally lean on her during the procedure. Similarly, Steve describes how “comforting” it is to him to “snuggle” with his mom. Junie says that during a painful procedure her mom is always there to hold her hand. It seems that while their bodies are weak and in pain, the soft caring touch of another is particularly comforting. Knowing that they are not alone, that they are loved and embraced, seems to help give them, as Steve said, the “courage” to face the “tough times.”

Interestingly, although each of the participants spoke of dreading the painful shots, blood draws, and bone marrow aspirations, they also each spoke positively about the doctors who order, and particularly the nurses who administer them. All of the
children spoke kindly of the nurses and doctors who care for them, even though the medical staff are the ones who most directly cause them pain & suffering. Alexis and Junie both spoke of the nurses and others in the clinic as “really nice.” Steve said that he has made some of his best friends, including a few of the nurses, since he has had cancer. Harry and Crystal mentioned that they like everybody at the hospital. Alexis fondly remembered that her doctor took the time to compliment her slippers as Alexis nervously awaited surgery. Harry enjoyed talking with the nurses about his favorite video games while he awaited or received treatment. The “nice” nurses made the children feel cared for and more comfortable even while in the hospital or receiving treatment.

Finding meaning. Though they have undoubtedly suffered, each of the participants spoke of at least one positive thing that has emerged for them since their diagnosis. Alexis spoke of her family making her feel loved and “special” after making it through her treatments and surgeries. Junie and Harry both spoke of feeling closer to their families and more aware of their support and love. Junie also said that having cancer has made her “braver” about her treatments and about “other things.” Steve and Crystal described the friendships they have forged with other children at the hospital and at camp. Steve also mentioned his work as raising awareness for cancer research and his desire to be a volunteer working with other kids with cancer. Each in his or her own way has found something meaningful in the way they have lived with their illness and in what they are now able to do and contribute to others. Indeed, their very participation in this study was a way for each of them to learn more and to use their experience to help other children living with cancer.
Discussion

*Moment by Moment*

This work began with a review of developmental theories and the development of children’s understanding of illness, treatment and death. After having a chance to explore children’s lived experiences, we can now take a fresh look at how developmental theories reveal the meaning of these experiences. Piaget (1972) describes the school-aged child as living in a *concrete operational* stage of development, one in which the child is still dependent upon applying operations to concrete objects or experiences in the child’s world. Erikson (1985) described the *school-age* as a period charged with issues of industry and inferiority as the child is *engaged* in learning new skills and competence. In both of these models we see the child’s ability to engage wholeheartedly in a project in the here and now. The children in this study demonstrated a striking ability to focus very concretely on the present, even to the point of compartmentalizing their experiences. Whereas Piaget viewed this focus on the concrete, the present moment and experience, as a limitation in the child’s ability to perform formal operations involving abstract thought, in the case of the children in my study, their focus on the concrete often allowed them to *live* and play, taking up the ordinary activities of childhood, without constant focus on the painful procedures yet to come or the possibility that they might not recover.

Being in the hospital, undergoing treatment and painful procedures was traumatic to these children. To draw themselves *in* the hospital or clinic was to recall being in an uncomfortable, often frightening environment. To avoid this, Steve and Harry drew themselves *outside* the hospital. They were able to draw the building or the lobby because nothing “bad” happened to them there. They focused on the details of the building’s exterior, the hospital sign, or the model trains on display in the lobby. This
demonstrated their immersion in these positive, or at least neutral, details that allowed them to depict the place without drawing focus to the negative experiences that have happened to them inside. Similarly, several participants were able to find ways to keep themselves distracted from upcoming procedures until they happened. Crystal focused on the drawings and interview and showed remarkable little anxiety right up until she was called back to receive her treatment, containing her anxiety until the moment she faced getting her shots. Afterwards, she wiped away her tears and jumped right back into the project at hand. Similarly, Alexis’ drawing of herself in the clinic focused solely on the table where we sat at that moment as seen from above, a classically dissociative perspective. Had she drawn the same picture from looking straight on at us at the table, she would have had to acknowledge the examination rooms just beyond the table. Instead, she tuned out the examination rooms and the clinic all around us, as if to say, “I’m here at this table now, not in there getting a shot. Until I have to go in there for my shot I’m not going to think about getting a shot.” This seemed less an outright denial, they knew what was coming, they seemed instead to try not to think or worry about what was coming until they had to. Their engagement in the activities of the here and now drew their focus from fears about the painful procedures to come. The ability to be totally focused and engaged in the task at hand, in the present moment, allowed them to live out the oft quoted expression, “taking it one day at a time.” In this way, though these children were of an age that they could understand their diagnosis and prognosis, they could acknowledge and sometimes worry that they could die from this cancer, they were not overwhelmed by these thoughts or feelings. They could reflect and discuss these concerns when they occurred to them, but for the most part, they were engaged in living life in the present, moment by moment. By the very nature of their developmental
context, these school-aged cancer patients may be less likely to suffer problems during or after their treatment (Marshall and Katz, 1989; Fritz & Williams, 1989). This engaged detachment may, in fact, be a part of what allowed these children to be happy and positive and full of life even in the midst of a life-threatening illness.

A comment I had often heard in the clinic, playrooms, and halls of the hospital, was that children often seem to cope with cancer better than adults. By the school age, children are intellectually able to conceptualize death, dying, life-threatening nature of illness (Marshall & Katz, 1989), but they do not seem to dwell on it in the way that adults so often do. Thoughts about the seriousness of their illness seem to occur to them like a bolt out of the blue. The participants in this study who were still involved in active treatment, however, did not seem to be preoccupied with thoughts of dying. This may be in some part a form of denial, a way of saying, “I’m not that sick.” But for these children it is also based in the reality of their experience and the information given to them by trusted adults.9 Like Crystal, who thought that cancer was like a cold that would take a few days to cure, these children are new to the idea of “cancer.” Upon hearing their diagnosis, they do not know what it means. Their doctors may tell them that with advances in treatment, the prognosis for many childhood cancers is actually quite good. With all of this as the backdrop, children may be aware that they have a serious life-threatening illness, and may even be aware that the specific cancer they have can kill children just like them, but until they experience cycles of remissions and relapses, or until their doctors tell them, as they told Steve, that they have exhausted all available treatment avenues, they have no cause to believe they have been given a “death sentence.”

As adults, we can remember when the diagnosis of many cancers did mean a

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9 This highlights the importance of our honesty with these children. They may not begin to prepare themselves for dying until we tell them and show them how to do so.
certain death – usually within a very short period of time. We also live with the experience that the cancers diagnosed in adulthood do not share such positive prognoses. Based on our knowledge and experience, given the diagnosis of cancer an adult’s whole existence could be tainted by the shade of death. Children’s optimistic attitude toward living with cancer, or at least their relatively low preoccupation with dying, can be realistic given the available treatment and prognosis of most of these children. Even Steve, who is actively coming to terms with a terminal diagnosis, still thinks of time in school years & sports seasons. He hopes to play football, while newly recognizing that the drugs may only be buying him time.

“Cancer and Me”

Spitzer (1992) found that her hemophilic participants struggled with being “different,” and in fact often disassociated themselves with terms such as “different” or “sick,” insisting instead that they were “normal” or at least not as sick as other kids. As I began this research, I questioned whether children with cancer would similarly struggle with identifying themselves as “patients,” and how this self-understanding might contribute to their experience of the illness.

With the exception of Steve’s references to his diagnosis and prognosis, the other participants in this study did not refer to themselves as “sick,” “different,” or even as cancer patients. This likely resulted from several factors. The participants in this study were all diagnosed within two years of our meeting, and were diagnosed within their memory (the youngest was 6 years old at the time of her initial diagnosis). They could all remember a time before cancer. Indeed, many described a desire to return to that time or a time in the future when they can be carefree (and cancer free). As a result, they may have viewed having cancer as, for lack of a better word, a phase, something that has happened...
to me, but which is not me – does not define who I am. Children diagnosed at an earlier age might not be as able to separate their understanding of themselves and their own identity from having cancer. For such children, living with cancer might be all they remember, and so naturally a part of who they understand themselves to be. Most of the participants in this study also have their focus on “cure” or remission, the time when this event, this phase of living with cancer would be past. This gives them not only a distinct time before they had cancer and now, but also anticipates a distinct time after cancer. These participants did their best to distance themselves from the hospital, their illness, any long-term effects of their illness (including the possibility of dying), and from being patients. They distanced themselves from the hospital and their illness, otherwise describing and drawing themselves as just smiling happy “normal” children. Each of the kids expressed at one time or another, their desire to be just a “normal,” carefree kid. Again, Steve was the one participant who differed in this respect. His doctors had told him that there remained little hope for a cure. He was coming to terms with the idea, as Bluebond-Langner (1995) describes, that “I am always ill and will never get better.” For Steve, the future that he imagined when he would be free of cancer and “active” again, was fading before him.

Finding Meaning Through Suffering

Similar to what other researchers described (Melamed, 1998; Fritz et al., 1987; Taylor, 1983), each of the participants in this study identified at least one positive event or change that has occurred to them since having cancer. These participants described having closer relationships with their families, friends they have made at the hospital and camp, and contributions they are able to make lending their experience to help other children with cancer. It may be, as van Veldhuizen and Last (1991) argued, that these
children are working to make sense of suffering from cancer “in such a way that it will be understandable, acceptable and endurable for them” (p. 1). What helps them to endure treatment is the goal of being cured. What helps them to endure the whole experience, especially when cure is not certain or no longer realistic, seemed to be the experience of being loved, supported, and cared for themselves and, in turn, caring for and helping others. These positive experiences give a sense of purpose to a patient’s time, whether it be the time remaining for a patient with a terminal prognosis, or making the most of a “good day” when he or she is not overly encumbered by the symptoms of his or her illness and treatment. Other researchers have positively correlated this ability to find meaning with patient’s ability to positively adjust to living (or dying) with illness (Fritz et al., 1987; Fritz & Williams, 1989; Taylor, 1983). These patients have had their mortality brought into focus in such a concrete way, that they are able to appreciate the importance of making the most of what may be their limited time. Each of the participants came to discover what making the most of each day meant to them. Whether it was Alexis’ basking in the love and special attention given to her by her family or Steve working as a cancer ambassador to raise awareness and funding for cancer research, each of these participants seems to be engaged in what Frankl (1959) described as the process of finding meaning in the face of suffering. Frankl (1959) argued that individuals can find meaning by (1) creating a work or through specific deeds, (2) through relationships and encounters with others, and (3) in the attitude they take towards suffering (p. 133). For adult or pediatric cancer patients, this ability to find meaning despite or in their suffering may indeed allow them to adjust and cope with their illness whether or not their treatment is ultimately successful.
A New Metaphor

In my review of the literature I discussed at some length what Kugelmann (1992) has named the “rhetoric of control” and war imagery that dominate much of the literature on coping with stress and illness. The techniques for coping could be seen through the lens of these dominant theories, however it is important to note that the language of control or of losing control, was not used by the participants in this study. For the purpose of dialoging with these theories, my participants could be described as having chiefly used secondary, or emotion-focused coping techniques to “control” or adapt emotionally to a situation rather than attempting to change the situation itself. It would indeed seem, as suggested above, that such techniques made sense given the fact that there was very little these children could do to in fact change their diagnosis or prognosis. The language of primary and secondary, problem and emotion focused coping seems to apply clear distinctions regarding an experience that, for my participants, was lived as a much more complex experience. This would seem to suggest that our experiences of stressful (or non-stressful, for that matter) events and our responses to them are rarely lived on one level, but are, I would suggest, almost always overdetermined. For example, Harry’s behavior of joking with his mother before a procedure could be classified as a mode of cognitive avoidance (Lazarus & Folkman, 1984; Spirito, Stark & Tyc, 1994). At the same time that Harry is avoiding anxious thoughts about the procedure, however, he is actively strengthening the emotional bond with his mother, and lifting both of their spirits. Cheering his mother also has the indirect effect of helping her to cope and maintain a positive focus, which in turn enables her to be a positive emotional support for Harry. Whether or not Harry directly intended this chain of events, his “coping technique” has far-reaching effects.
Beginning with the understanding of a patient’s behaviors as “coping mechanisms” meant to “control” situations or emotions, furthermore presupposes that such “control” is indeed possible. In the case of the pediatric oncology patients in this study, many facets of their situation are beyond their control. They are not able to take action that would alter their diagnosis, and, save from acting to follow a treatment regimen, nothing that would alter their prognosis. If treatments are unsuccessful, not only of their illness and treatment, but ultimately of their life and death may be beyond their control. Seen in this light, the struggle to “control” a situation that may be ultimately out of one’s control must be called into question. What would happen if instead of beginning with the premise that patients should or can act to “control” a situation, we began instead with the idea that much of what is happening to these patients is beyond their control? What do patients need in the face of losing control (of mundane aspects of their life, or ultimately of their life)? In this study, both the participants who seemed to have a positive prognosis, and the participant (Steve) who was coming to terms with a terminal prognosis, focused not on the control they maintained or lost, but on the care they received through each experience. Whether they were in the clinic for a painful procedure or a check-up, whether they hoped to complete a successful treatment course in a matter of months or their treatments had been unsuccessful, each participant spoke of the kindness, attention, and care given to them by their families and by the nurses, doctors and staff in the hospital. Knowing that this care and support was available to them seemed to help them endure whatever they were facing.

Within the metaphors of control and war that underlies much of the literature, the doctor-patient relationship is characterized by the image of a general and soldier battling the enemy that is disease. It is worth questioning, in fact, whether in this model the
enemy engaged is the disease itself or death. In either case, the “battle” must at least sometimes be a losing one. In this case, patient soldiers and doctor generals are left feeling, perhaps guiltily, that they have failed. Once it becomes clear that, as in Steve’s case, nothing more can be done, the general is left at a loss for how to continue the relationship with a now dying soldier. In fact, it is a good general’s duty to move on to continue the fight with other new soldiers who move in to take the place of the dying. The brave soldiers who fought valiantly, are left wondering how to re-orient themselves once they can no longer keep up the fight. How do they prepare for dying or for saying goodbye if all they have known to this point is “fighting to win?” It seems a new metaphor is necessary in order to guide these patients and their doctors through “successful” and “unsuccessful” outcomes – to inspire their relationships through remission, cure and life, or through the patient’s death.

Again, I look to the language and imagery used by my participants themselves. They consistently described the medical staff, particularly their doctors and nurses, not as generals, or super heroes who were going to save them from their illness. They may also hold such images of the medical staff, but in this study, they were not the images they described. They consistently spoke of the attention, care, and concern of the “nice” doctors and nurses. They understood that the medical staff had a job to do, that they wanted them to be well, and did not like to see them cry or in pain. It was in part this concern that helped make the painful treatments endurable for Crystal, Harry and Steve. With this notion of the concern of the professionals who attend to their needs with care, we may look instead to the image of guides, or sherpas, who lend their expertise to guide travelers along a difficult journey. The journey itself may be short or long, the path relatively straight and smooth, or steep and treacherous. Despite any obstacles that may
arise, however, the guide, or sherpa, never abandons their charge. Their mission is to
remains with the traveler, helping to clear the path, suggesting alternate routes, carrying
what may be carried of the burden as the climber makes his or her way.

Children in the Context of the Family

My participants all depicted “normal,” cohesive families, whether they drew just
one primary member of the family (e.g., Steve), or a larger extended family (e.g., Crystal).
In the drawings, family members are drawn in close physical proximity, a signal of the
child’s perception of a cohesive family unit that “stands together.” The children depicted
and spoke of themselves as a part of the whole family. In their drawings, families were
often engaged with one another in a common effort or task. The fact that these children
and their families were willing to volunteer to participate in this research speaks to their
already being a supportive cohesive unit. The parents that I interacted with were able to
talk about their child’s illness, and were willing to let their children talk about their
experiences as a part of this research project, with the hope that it might help their own
child and possibly other children with cancer.

During my interviews with Junie, Steve, and Harry, their mothers came in
towards the end of the interview to check on them and let them know they were nearby if
they needed them. Alexis described bringing her family together to play a game, one of
her favorite activities. Both Harry and Crystal described their families as “closer” since
they have had cancer. In one way or another, they described their families as being there
for them – standing by and supporting them through their illness. Paradoxically, having
to be dependent on their families, who have in turn proven themselves dependable,
allowed these children to develop the confidence and courage to become more
independent.
Implications of Method

To the children themselves. As previously mentioned, a significant limitation of much of the current literature involving hospitalized children is the reliance on reports from medical staff and parents to describe children’s coping behaviors or to corroborate or refute children’s self reports (e.g., Worchel, et al., 1987). This reliance on outside sources assumes a sort of suspicion as to whether children are able to adequately understand or describe their own experiences. This may stem from the cognitive-developmental foundation of much of the research on children’s coping, and from what Sipiora (1993) describes as Piaget’s failure to value children’s experiences and responses on their own terms. However, as we have seen, contemporary researchers including Eiser (1985), Jay et al. (1987), Redpath and Rogers (1984) and others have demonstrated that school-aged children do indeed have sophisticated illness concepts, often more so than their healthy peers. The current study demonstrates that school-aged children are indeed capable of understanding and describing their own experience both in pictures and in words. The participants in this study proved both willing and able to deliver rich and complex descriptions of their experience. Children are capable of being not merely the subjects of our research, but participants in our inquiry into what it means for them to live with life-threatening illness.

Advantage of the two-fold method. Previous research involving the use of interviews alone often yielded brief and guarded responses to the researcher’s questions (e.g., Jones, 2000). This is particularly true when the researchers and interviewers did not have an ongoing or therapeutic relationship with the participants. Coupling drawings with interviews involved my participants in a natural, fun activity that allowed them to “open up” by first showing me their world, and then narrating the story “behind” the
pictures. This lead to significantly more elaboration and attention to their individual experiences.

Outside of their use within a therapeutic context, the use of children’s drawings in hospital settings, has typically been as a means of diagnosing anxiety or depression. In those cases, the drawings of individual children are analyzed for similarity to drawings made by groups of depressed or anxious children (e.g., Clatworthy, Simon & Tiedeman, 1999; Tharinger & Stark, 1990). This may be a useful means of comparing data from large samples to determine statistical correlations, but leaves behind questions as to the meaning of individual experiences.

Piaget (1972) wrote that “whatever [their] answer may be, the meaning behind the words is what matters (p. 38). I would argue that both the child’s answer (i.e., their own narrative and pictorial account of their experience), and their meaning is what matters. The phenomenological method developed for this study was designed to take into account my participants as participants, that is, I involved them during the interviews in helping me to interpret and understand their lived experience. As I explained to my participants before we began our work together, they are the experts in what it is like to be a child living with cancer. By immediately calling upon them to help interpret aspects of their drawings and narrative accounts, I believe I was able to render analysis and interpretation that was faithful to their lived experience. It seems that to do otherwise would be akin to analyzing a dream without first coming to learn what meaning the dream images hold for the dreamer. In this study, for example, the image of two frowning nurses about to give tearful Crystal her shots immediately called to mind the interpretation that the Crystal saw the nurses as “mean” or “scary.” However when I asked her about this, Crystal was able to correct me, saying that the nurses were not “mean,” but “sad” because they did
not like to make her cry. This dialogue with my participants brought me to a more faithful and deeper understanding of their experience than any analysis of drawings alone.

I strongly recommend the use of the two-fold method of data collection and analysis developed in this study to other researchers as it seems uniquely suited to eliciting more elaborate and meaningful narratives from children. Through this two-fold process, I was able to gain access to the worlds of these children by engaging them on their own terms. In a hospital setting, this method would be a particularly helpful and efficient means of obtaining information regarding a child’s experience (i.e., his or her mood, context, strengths, weaknesses, hopes and fears). Such a method could aid in periodic assessment, continuing or long-term care, as well as in acquainting new members of the medical team.
Approach of the Researcher

Explication of Assumptions

As Wertz observed, “the researcher both finds and makes sense at the same time. Psychological insight is both a discovery and a co-creation.” (1985, p. 173). I came to this project with a great deal of respect for these children. I believe that the formative experiences of witnessing the playful children who seemed so much more alive than the adults in treatment beside them formed the foundation of two fundamental questions. First, is it true that these children can both comprehend the seriousness of their illness and cope well in spite of, or because of that knowledge? And secondly, if so, what helps them to cope well, even perhaps better than many adults?

Along the journey to complete this work, a number of influences in both my personal and professional life converged to shape the manner in which I conducted my research and the way in which I made sense of the data. I came to this phenomenon not only as researcher, but also as an existential psychologist, a Catholic, a psychotherapist, a daughter who lost a father to cancer, a teacher, and the mother of two young children. The values I carry with me entered into the questions that I asked and the meanings I saw in the data. After having completed the research, I reflect on my experience and assumptions to show my readers where to stand to see the participants and results from my perspective as researcher.

My training as a therapist and my instincts as a mother led me to feel very protective of my young participants. In designing my interview guide, I created a series of questions that allowed my participants a chance to ease into the interview process before delving into the more difficult aspects of their experience, and which eased them out of those reflections by asking them to recall the strengths, resources and support
available to help them cope.

During the interviews, I also allowed each child to be my guide in determining how far they wanted to go and how much they felt comfortable sharing. Once I rephrased and asked a question again, if the child continued shrugging his or her shoulders, said “I dunno,” or fell silent, I let it go. At several points in the interviews it is clear that my concern for the well-being of these children took precedence over pressing them to reveal more information than they may have been ready to reveal in this context. For example, during Steve’s interview (paragraphs 197 – 205), I wanted him to share more about living with a looming sense of danger. However, after several prompts and pauses, Steve did not seem ready to continue and so we moved on.

K: Ok. [pause] This next picture [drawing #2] looks kind of fun. Here’s you watching the trains and the plane. You’re smiling and saying “wow.” You told me that this would be you on your way out of the hospital, so whatever you had come in for was over. So it all looks pretty good. But then... [pointing]
S: [laughs] Yea. The plane’s on fire.
K: The plane is on fire. [pause] That made me think of your story of how you were diagnosed. You were going along, being active, being a kid, having a good time, and without you knowing - or all those doctors- that tumor was growing.
S: Yea. [pause]
K: So it was like this sort of happy scene that has this danger looming. Does that sort of fit for you?
S: Yea. I guess so. It’s kind of wacky.
K: Kind of wacky. Kind of scary.
S: Yea.
K: Yea. [pause] Ok. This one I already mentioned that these reminded me...

More information might have been gleaned on this topic if Steve had been discussing this imagery with someone with whom he had an ongoing, perhaps therapeutic, relationship. Given that I did not have that type of relationship with him, and using him as my guide, I
did not feel comfortable pressing him to reveal more.

As previously mentioned, my values stem in part from my training in an existential psychology program, being a Catholic mother of two small children, and having lost my own father to cancer. As I have reflected on this process, and particularly on my own interpretation of the interviews and drawings, I am made aware that I value attempts by my participants to find meaning in and through their suffering. I was particularly interested in their ability to find something positive that has come out of their experience of living with cancer. For example, I interpreted the very act of volunteering to participate in this research as a sign that they wanted to find a way to help others. My understanding of their involvement was as a meaningful attempt to help others by sharing their experience of living with cancer.

I also came to recognize more fully that as a researcher I am much less interested in cognitive-behavioral explanations for my participants actions, particularly when used to explain their motivation in acting. For example, when Alexis and Crystal described getting a toy as what helps them “get through the tough times,” I hoped to discover a deeper meaning beyond their reliance on a simple reward system. Crystal’s description of the nurses taking her to get a “prize,” showing the prize to her mother, and the nurse and her mother being “happy for [her],” led me to ascribe a deeper meaning, that beyond getting the toy, Crystal felt that these others cared for her and appreciated that she made it through the painful procedure.

Finally, in my discussion of the prevailing “control” and “war” metaphors in immunology and oncology, it is clear that I do not value the ability to “control” one’s situation and emotions or the ability to “fight to win” in the face of illness and death. Some of my concerns for this model are for the effect they have on a patient who is
dying. I find it disturbing as a therapist, mother, teacher of a class on death and dying, and daughter to think of a dying patient feeling guilty or despairing that they failed to overcome their illness, and ultimately that they *lost* the battle. My inclination to see doctors and health professionals not as generals in a war, but rather as guides along the journey, offering help, advice, and care no matter the path taken, reflects my own values and emphasis on the care of individual patients, including assuring that they are not abandoned once medicine can offer them no cure. Again, my own values and desire lead me want to see patients able to live fully, which for me includes, when possible, being able to recognize that the end is near and prepare themselves for a peaceful death, rather than “fighting” to the bitter end.
It was the goal of this research to make the experiences of children who live with cancer the heart of our journey to better understand and support them. In this way, I sought to render an account of children’s experiences that allowed the reader to “get to know” these children and to glimpse their world through their drawings. The purpose of the case-study style narratives used in this study was to more depthfully explore the experiences of children living with cancer. An obvious limitation of this approach, however, is that the results of case studies of five individuals cannot be generalized to apply to all children with cancer.

These interviews and drawings captured a moment in time with these children. As the interviews were conducted at the outpatient clinic of the hospital, I was able to see these children “in action,” coping with the anxiety of coming to the hospital for a checkup, to receive chemotherapy treatment or to undergo a procedure, such as a bone marrow biopsy. As a result of the timing of the interviews, I was able to see them in the middle of the “cancer world.” In future research, it might also prove valuable to also conduct interviews in a more neutral space, such as their homes. This more “normal” and relaxed context might allow participants to be less anxious and guarded in their responses. It would also be worthwhile to conduct several short interviews over a period of time in order to establish a relationship between the researcher and participants that might allow them to feel less guarded about sharing their experiences. In that case, researchers would also be able to compare and contrast children’s experiences, drawings and moods in multiple contexts over time. This study focused primarily on school-aged boys and girls with cancer. Variations in participants that might lead to new themes, include comparing...
the responses of boys and girls as well as younger children to older children. The interviews and drawings capture the child’s perception and mood at one moment in time. Different moments in a child’s treatment cycle, soon after receiving their diagnosis, during a remission, after a relapse, would likely yield variations in the results. Specific questions left unanswered in this research which would provide a stepping off point for future research include (a) the effect of children’s initial impressions upon receiving their diagnosis upon their continuing perception and experience of illness and treatment; and (b) the importance of children’s peers and friends in providing support to the children with cancer.


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Appendix A

Alexis

¹ Note on the format of appendices.
Interviews have been numbered by paragraph to facilitate references to interview dialogue within the meaning units and analysis. In each interview, the researcher’s remarks are preceded by “Kristy” in the first instance and “K thereafter. The participants’ remarks are preceded by their chosen pseudonym in the first instance and the first initial of the pseudonym thereafter.
[Chose her pseudonym, Alexis, after her favorite cousin. Alexis is a 7 year old caucasian female diagnosed 15 months previously with rhabdomyosarcoma.]

1. Kristy: It’s September 16 and this is Kristy with Alexis [all names and identifying information have been changed to protect confidentiality]. Would you like to say hi?

2. Alexis: Hi.

3. [tape recorder turned off and rewound to let A. hear her voice]

4. K: Like we talked about, I’m going to ask you some questions and have you do some drawings about what you think it’s like having cancer. Your mom is right outside if you need her for anything and we can always call T. [the child life specialist] if you want to talk to her. If you need to stop and take a break or just stop we can do that any time, ok?

5. A: Ok.

6. K: Now, I want to have you tell me about your experiences so that I can learn about what it’s like for you to have cancer. You can do the drawings any way that you like. You’re the expert, so you can’t give a wrong answer, ok?

7. C: Ok.

8. K: All right. This first page will help me get some information about you. So, first you can write in how old you are right here.


10. K: That would be great. OK. Now this second question says “I found out I had cancer...” You can write in how old you were when you first found out or how many months or years ago that was.

11. A: What do I write? Just 5?

12. K: You were five years old?

14. K: Yes, then you can just write in 5.

15. A: [writes in “5”]

16. K: OK. Now, “The kind of cancer I have is called...” Do you know the name of the cancer you have?

17. A: I know it, but I can’t spell it. [laughs]

18. K: That’s ok. What is it called?

19. A: Rhabdomyosarcoma. It’s a cancer of the muscle.

20. K: OK. Why don’t you write in “cancer of the muscle” and I’ll spell it out.


22. K: m-u-s-c-l-e. That’s a tricky one, huh?

23. A: [writing]

24. K: Now “That means...” How would you explain what rhabdomyosarcoma is to someone who didn’t know?

25. A: It’s a lump?


27. A: [writing] Is that how you spell lump?

28. K: It sure is. Is there anything else you could say about what that means if a friend asked you?

29. A: um... It’s a type of a cancer.

30. K: OK.

31. A: [writing] How do you spell type [had written “t-i”]?

32. K: It’s t-y-p-e.
33. A: [laughs] It’s what?

34. K: [laughs] t-y-p-e.

35. A: Don’t worry, I can change it. [writing] There. That “i” looks like a “y” now, doesn’t it?

36. K: Yes it does. That’s great. [taking paper and pen]

37. A: I’m going to eat my chips and drink my juice. I’m doing work. [A. had not been able to eat or drink for 12 hours prior to a procedure she finished just before our interview.]

38. K: That’s just fine. Ok. Let’s do some drawing now. I’m going to have you do five pictures all together. You can draw them any way you want and use any colors that you want. Ok?


40. K: Here is your first piece of of paper. And here are your crayons. Now the first thing I want you to draw is a picture of yourself.

41. A: OK... [begins drawing #1] ... This is supposed to be the chair. [smiling and laughing while drawing] There’s a chair. [drawing] OK

42. K: Great. Do you want to add any colors or anything else?

43. A: Nope. Do you know what that is? [pointing to drawing]

44. K: Is that your chair?

45. A: It’s a chair, a desk with me drawing a picture.


47. A: With my tongue sticking out.


49. A: That’s how I draw – with my tongue sticking out. [laughing while she
50. K: Do you think this picture describes you pretty well?

51. A: Yes, because I like to draw and I like to stick my tongue out while I’m drawing.

52. K: Are there any other things you can think of that describe who you are?

53. A: um...

54. K: Any words that help describe you or any other things that you like to do? You can write them down on the paper or just tell me.

55. A: I like to ride my bike.

56. K: Ride your bike.

57. A: And swim.

58. K: And swim.

59. A: And play with my Barbees. I like to get toys.

60. K: Any other words that describe you?

61. A: I like to go to Las Vegas.

62. K: Las Vegas? Have you been to Las Vegas?

63. A: I was born there.

64. K: Oh, were you really? Do you have family there or do you just like to visit?

65. A: I like to visit there. That’s where my cousin lives.

66. K: Anything else that describes you – like, I’m a sister, or friendly, or an artist, or funny?

67. A: I’m an artist.

68. K: You’re an artist?
69. A: Yes. I won a drawing contest.

70. K: That’s great.

71. A: [drops a chip on the floor, quickly picks it up and pops it into her mouth] It’s still good. [laughing]

72. K: [smiling] Is there anything you can think of that doesn’t describe you, like “I am not shy,” or “I am not mean”?

73. A: I am not mean. I don’t have a sister. Well, I have two sisters, but they’re a dog and a guinea pig. They’re both girls. Want to know their names?

74. K: OK

75. A: The dog is called Scarlett and the guinea pig is named Cinnamon.

76. K: Is there anything about your drawing that you would change to describe yourself before you had cancer? Is there anything that you would draw differently?

77. A: um....

78. K: Or anything you can think of to describe yourself before you had cancer?

79. A: [popping a chip into her mouth] Eating. I would have drawn myself eating.

80. K: Eating. OK. Can you tell me about how that is different now?

81. A: That I don’t eat as much when I’m sick in the hospital. I don’t like the food here.

82. K: You don’t like the food in the hospital?

83. A: No. It’s not good. When I’m well I eat lots.

84. K: OK. Is there anything else?

85. A: um... no

86. K: Is there anything about your drawing that would be different in the future?
87. A: um... how do you mean?

88. K: If this was a picture of you several years from now?

89. A: um... I’d be fourteen.

90. K: OK. What would you draw differently if you were fourteen?

91. A: Me and my cousin getting our nails done. She’ll be really old then. She’ll be thirty-something.

92. K: OK. Anything else that would be different in the future.

93. A: No. Just a picture of me and my cousin doing our nails.

94. K: OK. So this will be your second drawing. Here I would like you to draw a picture of yourself in the clinic or the hospital. You can draw it any way you want and use any colors that you want.

95. A: hmmm... [beginning drawing #2] Is that a weird table?

96. K: That’s a fine table.

97. A: These are all the chairs here.

98. K: Sure. I can see that.

99. A: [drawing] OK

100. K: OK.

101. A: More... [laughing]

102. K: More? OK

103. A: [laughing] My food. ... [drawing] and a box of crayons [drawing] ...and the tape player [drawing] There. There’s my table. [handing drawing to me]

104. K: OK

105. A: [laughing] I draw little pictures for a big piece of paper, don’t I?
106. K: That’s ok. So tell me about your drawing.

107. A: It’s you and me sitting at the table.

108. K: You and me at the table, I see that.

109. A: Yep. There’s you writing and me drawing. I drew it so you could see everything.

110. K: Can you tell me a little bit about what it’s like to be in the clinic or in the hospital?

111. A: um... You get toys a lot.

112. K: You get toys a lot?

113. A: And I don’t like to be poked with a needle in your hand or your arm for an IV. There’s a gift shop that I like, but I don’t get anything from there very much. And... one more thing – everyone’s nice.

114. K: Everyone’s nice?

115. A: Yes.

116. K: What do you like about them?

117. A: They’re just really nice. um... Things that I like?

118. K: Yes.

119. A: Then I shouldn’t put Dr. K. in there. [laughing] because he’s always [tapping at her arm].

120. K: He... sticks you with a needle?

121. A: No.

122. K: No?

123. A: [tapping her arm again at the wrist]
K: late? [laughing]

A: Yes! [laughing] He didn’t call me earlier. We sat there for like two and a half hours.

K: So you don’t like waiting?

A: No. Doctors keep you waiting.

K: Doctors keep you waiting?

A: Yep. [taping wrist and laughing] What is the worst part about waiting?

A: It’s boring.

K: Is there anything else about the clinic or the hospital that you like or don’t like?

A: I don’t like the smell.

K: The smell?

A: Yea.

K: Can you tell me about the smell?

A: It’s just gross.

K: It’s gross?

A: Yep.

K: OK. Anything else you can think of?

A: No. That’s it.

K: How do you feel when you’re at the clinic or in the hospital?


K: Yeah?
A: When I get poked by a needle.

K: When you get poked by a needle?

A: It hurts. I don’t like needles.

K: Can you tell me about getting needles or IVs?

A: I scream when they do that. They push it in and out and in and out. It hurts.

K: I bet that hurts. So you don’t like when they are poking you. What about before they poke you?

A: Scared. I look at it and all around and at it and around the room. I don’t like that.

K: OK. Drawing number three. Are you ready? You can use any of the crayons that you want to.

A: I’m using black. My prom dress is going to be black.

K: Your prom dress is going to be black?

A: Yes.

K: You really like black?

A: Yes.

K: OK. Drawing number 3. I want you to draw what you think is the worst thing about having cancer.

A: [beginning drawing #3... laughing at self figure just drawn... changing smile to frown] [drawing...] [laughing at doctor figure] See that?

K: That’s a good job. I can see what that is.

A: “I’m coming in. Here comes your IV.” [laughing]

A: [laughing] The pillow looks like a big stone.

K: A big stone? The pillow?
163. A: Yea. [laughing]

164. K: Do the pillows at the hospital sometimes feel like stones?

165. A: Yes!

166. K: They’re not the greatest pillows? Not very comfortable?

167. A: Not at all! [laughing and drawing... laughing nervously and whining while drawing next figure] That is surgery.


169. A: My surgery. [laughing and whining]

170. K: Oh, surgery. And this is you in the middle?

171. A: There are two coming at you at once. I have to go to surgery and I have to get my needle shot.

172. K: At once – two at one time. Does that often happen? You have to do a bunch of things at once.

173. A: Yea. We do lots and lots of stuff. [putting down crayon]

174. K: So tell me about your drawing. Who are these people? What are they doing?

175. A: I don’t actually know who these people are, but that one [figure on left] is going to do surgery.

176. K: And what has he got there?

177. A: Scissors.


179. A: And that one is trying to give needles

180. K: He’s holding a needle there?

181. A: Yep. And I just don’t know what to do.
182. K: You’re in the middle and you don’t know what to do?

183. A: Yea. [whimpering and laughing] That one is evil [pointing to figure with needle].

184. K: That one is evil?

185. A: He looks evil because his eyes going like that.

186. K: So how do you feel when you are about to get a shot or you’re trapped in the middle having to do two things...

187. A: Trapped in the middle! [nodding head and laughing]

188. K: Is that right?

189. A: Yea. I’m scared and stuff.

190. K: What do you think about or what do you do?


192. K: Scared because it hurts or because you don’t like to be there or don’t know what to do?

193. A: All of those.

194. K: All of those. OK. So what would this girl in the picture be thinking?

195. A: It’s me!


197. A: I just don’t know what to do because I have to take my surgery and I have to get my IV. I don’t know which one to do.

198. K: You don’t know what to do. Do you feel that way a lot?

199. A: Sometimes.
200. K: Sometimes? You sometimes feel like you’re stuck in the middle when all these things are going on and you don’t know what to do?

201. A: Yea. [picking up crayon and adding patch to her arm in drawing]

202. K: And is this a Band-Aid on your arm?

203. A: No. It’s the patch where the IV goes.

204. K: OK. Anything else you can think of to tell me about this drawing?

205. A: No.

206. K: No? OK. For this one I want you to draw what helps you get through the touch times.

207. A: Like what?

208. K: Like getting a needle shot or just having cancer. What helps you get through that?

209. A: [beginning drawing #4] There! That one looks like more like a pillow! [laughing... drawing] Now I have to draw ears to get that over. [surgical mask on face of second figure] [drawing... laughing as finishes drawing and puts down crayon]

210. K: All right. So tell me about your drawing. What have we got here?

211. A: OK, see... This one is kind of violent. [laughing]

212. K: It’s violent?

213. A: Yea. I’m ready to have my surgery, but I don’t really want to go. I’m going to get a tumor out, but I really don’t want to do that because I don’t like surgeries. This is my very first surgery. I was kind of scared so I didn’t want to go. And he’s got scissors and a knife!

214. K: What is it? He has scissors and a knife.

215. A: Yea. He’s going to cut me open, stick the tumor into the knife [making a stabbing motion] and he’s going to put it on this little thing.
216. K: Oh, wow. So when you had your surgery what helped you get through that?

217. A: Well, they promised me that I get a toy at the end [pointing to drawing] so I just go with it. Actually I really do get a toy. They weren’t lying. This is a little teddy bear I got.

218. K: So when you had surgery or when you have to do something hard you think about getting a toy when it’s all over and focus on when it’s going to be all done.


220. K: And this teddy bear is right in front of you here, so you almost can’t see the knife and the scissors, huh?

221. A: Yep.

222. K: Is there anything else that helps when you’re scared or you’re about to have a procedure?

223. A: [shakes head]

224. K: Anything that you do or think about or that other people do that helps?

225. A: [shaking head]

226. K: Not really? You just think about when it’s going to be over.

227. A: [nodding head] My very first surgery the doctor sure liked my shoes. They were like pink slip off’s that light up.

228. K: OK. And that helped when he talked about your great shoes?

229. A: [nodding head]

230. K: OK. When you think about this drawing when you were about to get your surgery how were you feeling?

231. A: Scared and nervous.

232. K: And they told you that you would get a toy when it was all over?
A: uh huh.

K: And how did that make you feel?

A: Happy.

K: Happy? And did you just think about what kind of toy you were going to get and playing with it when you were all done?

A: [nodding head]

K: And that helped you not be so scared and nervous?

A: Yea.

K: Is there anything else that helps you feel better when you’re feeling bad or when you’re scared? Anything else you can think of?

A: [shaking head]

K: When the doctor is nice and notices your shoes, right?


K: All right. For this next picture I want you to draw you and your whole family with everyone doing something.

A: [beginning drawing #5]

K: Are you all done?

A: [nodding]

K: OK. Tell me about your drawing. Who’s who and who is doing what?

A: [pointing] This is my mom. This is me. This is my brother. This is my dad trying to get a piece under the table. Like this [laughing and demonstrating].

K: He’s getting something that fell down with his foot?

A: Yea. We’re playing Monopoly.
252. K: So when something falls down is it your dad’s job to pick it back up again?

253. A: Yea. He doesn’t want to do it, but he’s doing it. And he’s [brother] smiling that he doesn’t have to get it.

254. K: Do you like to play games with your family?

255. A: Actually, I do the most. Sometimes some people will play with me, and then I get to play.

256. K: OK. So tell me about your family a little bit. Does this picture describe them pretty well?

257. A: [nods head]

258. K: How would you describe your family?

259. A: We’re all here [in the clinic] except one more person, my brother. He’s at school. [picks up crayon and labels figures in drawing]

260. K: Do you like to play games and do things together?

261. A: Not really, but sometimes we do.

262. K: Do you like it when you do?

263. A: Yes.

264. K: Can you tell me about your brother?

265. A: He likes video games. [whispering] He’s addicted. [laughing]

266. K: Oh, yea. Does he play all the time?

267. A: Yea. All he thinks about is games, games, games.

268. K: And how old is he?

269. A: Fourteen.

270. K: Do you play together a lot or not so much?
271. A: A lot.

272. K: A lot? Do you like your brother?


274. K: That’s great. Does he look out for you as a big brother.


276. K: Really? How does he do that?


278. K: Oh, he would?


280. K: OK. Well, let’s have a look at your drawings together, and we’ll talk about them for just a minute. Then we’re all done. I’ll tell you what I noticed about your drawings and you can tell me if what I say sounds right to you. OK?

281. A: OK.

282. K: You told me when you first started drawing that you drew a little drawing on a big piece of paper.


284. K: Do you usually draw pretty small pictures?

285. A: Sometimes. This time I did.

286. K: OK. When you’re drawing pictures on your own do you like to use a lot of colors or do you like to use just one at a time?

287. A: [shrugs shoulders]

288. K: It depends?

289. A: It depends on the picture.
290. K: When you’re drawing by yourself what kinds of pictures do you like to draw?


292. K: OK. Do you use lots of colors when you’re drawing those?

293. A: Yea.

294. K: In all of these you used black, right?

295. A: Yep. [smiling] I was working.

296. K: You were working. OK. So it wasn’t a drawing just for fun, huh?


298. K: OK. I noticed that in almost all of your pictures – except this one [drawing #4] you’re smiling. And even this one [drawing #3] you started out smiling.


300. K: Are you a pretty happy person?


302. K: Everybody is smiling in this one, huh?

303. A: Except my brother, he doesn’t want to play.

304. K: He doesn’t want to play?

305. A: He’s bored. And my dad is picking up the piece that fell.

306. K: OK. Everybody in your family is pretty close together in this picture. Are you all pretty close?

307. A: Yea. [smiling]

308. K: OK. In this one [drawing #4] the teddy bear is right up close to your eyes. It’s like that is what you were focusing on instead of the surgery.
309. A: Yea.

310. K: OK. Is there anything else you can think of? If you had a friend who was diagnosed with cancer is there any advice you would give them? Anything that you know now that you didn’t know before?

311. A: That... it’s kind of hard to get the IV’s in your hand, because they go in and out and in and out. It hurts a lot. Except when you get a toy. Every poke you get a toy.

312. K: And that helps?

313. A: After I get a poke I get a toy. [laughing]

314. K: Anything else that you can think of?

315. A: Nope.

316. K: OK. How did you feel about doing these drawings and talking about them?

317. A: OK.

318. K: OK? Do you have any questions for me?


320. K: OK. Well, I think we’re all done then. Thank you for all of your help.

Follow-up questions. 11/10/03

321 K: I hear that your hair is growing?

322 A: Yep. It’s all the way down to my neck almost to my shoulder.

323 K: Wow! That is long. Does it look the same?

324 A: I don’t know. I think it’s a little bit darker.

325 K: Well, ok. I have a quick question for you.
326 A: Ok.

327 K: Do you think having cancer has changed your life in any way?

328 A: Yeah.

329 K: How do you think having cancer has changed your life?

330 A: The good thing is getting toys when I get a shot.

331 K: Getting toys when you get a shot. Absolutely. What else?

332 A: (laughs) After I get a scan I get a toy.

333 K: (laughing) I remember after I first met you you’d had a scan and had a brand new Barbee doll.

334 A: Right.

335 K: Do you think having cancer has changed who you are or how you think about yourself at all?

336 A: I lost my hair. Then I grew it back.

337 K: Ok. Do you think anything positive has come out of the experience for you?

338 A: It made me special!

339 K: It made you special?

340 A: Uh huh.

341 K: Can you tell me about that?

342 A: Well... I have a lot of attention.

343 K: A lot of attention?

344 A: Yeah. (pause) And that’s it.

345 K: What kind of attention. Can you give me an example?
A: My... well... I don’t know. That’s it.

K: That’s it? Ok. How do you feel about all that attention.

A: Special!

K: Special. That’s right. Do you like that attention?

A: Yes.

K: Ok. Do you think having cancer has made you different in any way from other kids your age?

A: Yeah.

K: Yeah? How so?

A: Well... I didn’t have any hair – last year. And that I have cancer.

K: That you have cancer?

A: Yeah. They didn’t ever have it.

K: They didn’t have it?

A: They haven’t had scans and been to the hospital. And had surgeries.

K: Ok. So you have been through a lot of things that other kids your age haven’t.

A: Right.

K: Ok.

A: Do you know how many surgeries I’ve had?

K: No. How many?

A: Five!

K: You had five?
A: Yeah. Just when I was just six and seven.

K: Wow. Anything else that you can think of?

A: Well... I took Zoloft that helped me not be sad.

K: You took Zoloft when you were sad?

A: Yeah.

K: Can you tell me about being sad before? What were you sad about? What was that like.

A: I was sad because I didn’t like being sick.

K: You didn’t like being sick?

A: Yeah.

K: Can you tell me about that?

A: I just didn’t like it. And that’s it.

K: Ok. Were you sad about just being sick, or being in the hospital or...

A: Yep. All of it. I just didn’t like it.

K: Ok. And the Zoloft helped you not feel as sad?

A: Yep.

K: Ok. I have just one more question for you. Your mom told me that when you first got diagnosed that you didn’t want to say the word cancer. She said that you made up a different word for your family to use?

A: Yeah. (laughs)

K: What’s your word?

A: (melodramatically) “The horror.”
K: Ok. The horror. What made you want to use that word?

A: Because it’s evil.

K: Because it’s evil? Ok. How does your family like using that word instead?

A: Well, sometimes I let people say cancer, but... it was the shortest word I could think of.

K: It’s a pretty good description. It is pretty awful and evil, isn’t it?

A: Yeah.

K: What didn’t you like about the word “cancer”?

A: I just don’t like it.

K: You just don’t like it?

A: No.

K: Ok. What do you like about saying “the horror” instead.

A: (laughs) It’s evil... and it’s funny. It’s my word.

K: Ok. It’s funny. Does it make them laugh when they use it?

A: Yea, sometimes.

K: Ok. Let me ask you one more thing. When you were saying that you get a lot of toys when you have cancer, what is your favorite part of getting toys?

A: Playing with them.

K: Playing with them. Sure. Does it make you happy that your mom and dad get you the toys? That they want to do something special for you after you’ve had a shot or a scan?

A: Yes.
K: Yes? Do you usually have something in particular that you want or do they surprise you?

A: They love me – I get to pick it!

K: Ok. Anything else that you can think of?

A: Nope.

K: I’m glad to hear you’re doing so well.

A: When I get my scan are you going to be there?

K: I might be. When do you go in?

A: I don’t know. They’re going to call and tell me.

K: Ok. So maybe I’ll see you up there one of these days. Take care of yourself, ok?

A: Ok.
Kristy Novinski

190

Children’s Experience of Cancer

A2
Kristy Novinski

191

Children’s Experience of Cancer

A3
Kristy Novinski

192

Children’s Experience of Cancer

A4
Kristy Novinski

Children’s Experience of Cancer

A5
Name: Alexis  Age: 7  Drawing # 1  Time: 3 minutes

Tongue sticking out (at the viewer / me) Immediate self portrait. Drawing self drawing (tongue in cheek)

Position of Self: sitting in a chair – more dependent posture, could reflect need for support

Action: Sitting, drawing

Size and Proportion
  - Self: 1/3 page. Proportional to (child-sized) desk. Somewhat small in relation to environment (paper)
  - Non human figures: desk, crayon realistically proportional to figure

Spatial Relationships
  - Human figures: n/a
  - Non human figures: sitting at table drawing (transparency). Arms outstretched across table

Facing: facing out of picture (towards viewer)

Facial Expressions: smiling (tongue out)  Eyes: looking out

Use of Color: 1 used – Black outline, no additional color or shading. Anxious? (no energy to chose multiple colors)

Use of Paper: 15%

Placement on Paper: Centered in lower third – grounded / realistic. Table and feet grounded at the bottom of the page

Presence/Absence of Medical Instruments: none

Emphasis/Exaggeration/Omission of Body Parts: Extended arms to reach across table. No hands, feet, ears (not unusual for age)
Drawing Analysis Worksheet

Name: Alexis  Age: 7  Drawing # 2  Time: 5 minutes

Overhead perspective. Can see “everything” on the table, but nothing of the clinic. Very focused on getting details of what is right in front of her – tuning out rest of clinic.

Position of Self: Sitting at table – may reflect more passive position, need for support
Action: Sitting, drawing

Size and Proportion
  Self: Small in relation to environment (paper), but correctly / realistically proportioned in relation to adult and objects. Significantly smaller than in other drawings.
  Other human figures: Slightly larger than child – realistic proportions
  Non human figures: table, chairs – realistic

Spatial Relationships
  Human figures: Researcher sitting beside A. at table. No contact, but proximal.
  Non human figures: Realistic spatial dimensions.

Facing: Seen from above – top of head and facing away. Cannot see face / expression. No face to be seen in clinic.

Facial Expressions: Can’t be seen from overhead perspective – ambiguous / veiled
Eyes: n/a (see above)

Use of Color: 1 used – black outline. No additional color or shading. Anxious? (no energy to chose multiple colors)

Use of Paper: 10% (larger table than in 1st drawing, depicted smaller – farther away – more distant here) Smaller figures

Placement on Paper: bottom center – insecurity or desire for grounding / realism.

Presence/Absence of Medical Instruments: None – notable in a drawing of the clinic

Emphasis/Exaggeration/Omission of Body Parts: n/a (no hands, feet, ears – not unusual for age)
Drawing Analysis Worksheet

Name: Alexis  
Age: 7  
Drawing # 3  
Time: 4 minutes

Trapped in between doctors / scary, painful procedures. A. looking worried (changed from smile). More attention to detail in scissors, bed than to figures (no clothes, etc.)

Position of Self: Standing

Action: Standing. Inactive – immobile “I don’t know what to do”

Size and Proportion
  Self: Drawn as large as doctors
  Other human figures: proportionate to one another and objects
  Non human figures: proportionate

Spatial Relationships
  Human figures: Somewhat distant. Approaching – no contact, but moving toward A. (threatening)
  Non human figures: bed, figures holding (brandishing) scissors and needle

Facing: Out
Facial Expressions: worried (wavy smile)
Eyes: pin point – watchful

Use of Color: 1 used – Black outline with no additional color or shading. Anxious? (no energy to chose multiple colors)

Use of Paper: 35% – (As in previous drawings, not utilizing full space. Self & others small – scene is small (far away, distanced?)

Placement on Paper: Grounded at bottom of page – insecurity or desire for grounding / realism

Presence/Absence of Medical Instruments: Bed, scissors (A. associates with surgery “cutting me open”), needle and IV patch on A.

Emphasis/Exaggeration/Omission of Body Parts: No hands, feet, ears (not unusual for age)
“What helps you” drawing is the most “violent” so far. Can’t see what doctor is doing because of toy in front of her eyes (in her mind’s eye).

Position of Self: Lying down on bed, prepped for surgery. (Passive, defenseless position)

Size and Proportion
Self: As large as dr. Small in relation to paper, proportional to rest of scene – somewhat smaller than self in #1 and #3.
Other human figures: Good proportion in relation to other objects
Non human figures: bed, medical instruments and toy in good proportion to human figures

Spatial Relationships
Human figures: Dr. hovering above A. about to touch » cut. “violent”
Non human figures: Toy on A’s head – blocking view of Dr. and medical instruments

Facing: A. facing up, looking at toy. Dr. facing out
Facial Expressions: Dr. covered by mask, A. expressionless (anxiety, frozen, concentrating on toy). Eyes: Pinpoint – looking out

Use of Color: 1 used – Black outline. No additional color or shading. Anxious? (no energy to chose multiple colors)
Use of Paper: lower quarter
Placement on Paper: centered at bottom of page – insecurity or desire for grounding / realism

Presence/Absence of Medical Instruments: Bed, scissors and knife – Instruments for surgery

Emphasis/Exaggeration/Omission of Body Parts: No arms. (Passive, defenseless; no way to stop what is happening) No hair (1st in series to have self with no hair). No hands, feet – not unusual for age. Dr. has ears (1st in series) – functional – to hold up mask
Drawing Analysis Worksheet

Name: Alexis  
Age: 7  
Drawing # 5  
Time: 4 minutes

All together in common activity / project. Children framed by parents at round table (no head – leader/status). Humor in depiction of dad.

Position of Self: Sitting at table to play game. (More passive position, desire for support » appropriate to scene)


Size and Proportion
- Self: Small in relation to page, but realistically proportioned to adults and table
- Other human figures: Mom – large profile eye, dad partially under table
- Non human figures: realistically proportioned in relation to figures

Spatial Relationships
- Human figures: No contact, but proximal. Around table together. Engaged in common project / activity / game
- Non human figures: table, game, chair (functional)

Facing: Self out. Mom facing dad directly & kids indirectly, dad & kids facing out (at round table all more or less facing each other)

Facial Expressions: Self – smiling, mom – smiling, brother – smirk (making dad pick up piece), dad - expressionless (retrieving piece from under table)

Eyes: Mom has large eye with pupil: watching over family

Use of Color: 1 used – Black outline. No additional colors or shading. Anxious? (no energy to chose multiple colors)

Use of Paper: 1/3

Placement on Paper: centered at bottom of page – (insecurity or desire for grounding / realism)

Presence/Absence of Medical Instruments: – none – (appropriate for scene)

Emphasis/Exaggeration/Omission of Body Parts: no depiction of hands, feet, ears (not unusual for age); no hair as in previous drawings
Demarcation of Meaning Units

1. Paragraphs 8-9
   A. gives the additional information of her birthday.

2. Paragraphs 10-15
   A. asks for clarification on how to correctly answer a question.

3. Paragraphs 16-17
   A. laughingly tells me that she knows the name of the cancer she has but does not know how to spell it.

4. Paragraphs 18-19
   A. has Rhabdomyosarcoma, a cancer of the muscle.

5. Paragraphs 21-23
   A. asks for help spelling “muscle.”

6. Paragraphs 24-25
   A. explains that her cancer is a lump.

7. Paragraph 27
   A. confirms the spelling of “lump.”

8. Paragraphs 28-29
   A. explains that Rhabdomyosarcoma is a type of cancer.

9. Paragraphs 31-35
   Alexis asks for help spelling “type.” When she discovers a misspelling she laughs and corrects her mistake.

10. Paragraph 37
    A. tells me that she will be eating and drinking while she works [during the interview].

11. Paragraph 41
    A. smiles, laughs and explains to me what she is drawing as she completes the first picture.
When asked if she would like to add any other colors to her picture, she declines.

Alexis asks if I know what she has drawn. She explains that she has drawn herself sitting at a desk drawing a picture with her tongue sticking out as she likes to do while she draws.

A. thinks this drawing describes her well, doing something she likes to do.

A. also likes to ride her bike, swim, play with Barbees and get toys.

A. also likes to visit Las Vegas where she was born and where her cousin lives.

A. says that she is also an artist and that she has won a drawing contest.

A. drops a chip but laughs and jokes that it is “still good” as she continues to eat.

A. says that she is not mean.

A. says that she does not have a sister, except, she jokes, for her two female pets.

A. says that if she had drawn herself before she had cancer she would have drawn herself eating – when she is well she eats lots. She doesn’t eat as much when she is sick because she doesn’t like the food in the hospital.

A. says that if she were to draw herself in the future, seven years from now, she would draw her and her cousin doing their nails.

A. explains that she is drawing a table and chairs as she completes the second picture.
A. adds her food, the box of crayons and the tape player all also in black.

A. laughingly notices that she has drawn little pictures on the big pieces of paper.

A. explains that in her drawing of herself in the clinic she has drawn herself and me sitting at the table with her drawing.

A. says that she drew the picture of herself in the clinic so that you could see everything [on the table].

In describing what it is like to be in the clinic, A. says that you get toys a lot.

A. doesn’t like getting poked with a needle in her hand or arm for an IV.

A. says that at the hospital there is a gift shop she likes, but does not get things from there very often.

A. says that everyone at the clinic is nice.

A. says that she doesn’t like Dr. J because doctors make you wait.

This morning A. had to wait for two and a half hours for her scan.

A. thinks the worst thing about waiting is that she gets bored.

A. does not like the gross smell of the hospital.

A. feels “screamy” sometimes when she’s in the clinic or the hospital.
A. screams a lot when she gets poked by needles in the clinic. It hurts her when they push the needles in and out.

A. doesn’t like before she gets poked, either. She feels scared as she looks back and forth from the needle to around the room.

Reminded. as she begins the third drawing that she can use any of the crayons. She reasserts that she wants to use black, a color she really likes and even wants as the color of her prom dress.

A. laughs and jokingly whines as she draws the “worst” thing about having cancer, including the doctor coming to give her IV.

A. laughs at the pillow she has drawn which looks “like a big stone.” She laughingly admits that the pillows at the hospital are very uncomfortable like stones.

A. laughs nervously as she draws herself between two doctors.

A. has drawn herself before her first surgery with herself between a doctor with an IV and a surgeon with scissors.

A. says that the figure with the needles is “evil” because of the way she has drawn his eye.

A. feels scared in situations like this when she is “trapped” in the middle, not knowing what to do first.

A. feels scared because procedures hurt and when she doesn’t know what to do.
Paragraphs 194-196
When asked what the girl in the picture is thinking A. teases reminding me that it is her in the picture.

Paragraphs 196-201
In this picture A. doesn’t know what to do. She has to have both procedures and doesn't know which to do first.

Paragraphs 201-203
A. adds an IV patch to herself in the drawing.

Paragraphs 206-208
A. asks for clarification on what she is to draw in the fourth drawing.

Paragraphs 208-209
A. laughs and talks about what she is drawing including a pillow that she proudly says looks “more like a pillow” than her earlier attempt.

Paragraphs 209-213
A. warns that this drawing depicting her first surgery is “violent.”

Paragraph 213
A. describes being scared to go to her first surgery.

Paragraphs 213-215
A. points out that the doctor figure in her drawing has scissors and a knife. She describes the surgery where he will cut her open, put the tumor on his knife [stabbing], and put the tumor on a tray.

Paragraphs 216-219
What helped A. get through her first surgery was the promise that she would get a toy once it was over, which she did.

Paragraphs 220-226
A. says that nothing else she thinks about or that she or other people do that helps her to get through procedures other than thinking about when it will be over.

Paragraphs 227-229
It helped A. before her first surgery when the doctor liked and talked to her about her shoes.
Before her first surgery A. felt scared and nervous.

A. felt happy when she was told she would get a toy after her surgery. She focused on that to get her through the surgery itself.

A. can’t think of anything else that helps her to feel better when she is feeling bad or scared except for the nice doctor who noticed her shoes.

A draws a picture of her mother, herself, her brother, and her father playing Monopoly.

In the drawing A’s dad doesn’t want to, but is trying to get a piece that fell under the table while her brother smiles because he didn’t have to do it.

Out of her family A. likes playing games the most. Sometimes when the others will play with her she gets to play.

A. agrees that this drawing describes her family pretty well.

A. points out that all her family[mother and father] are at the clinic except for her older brother who is at school.

A.’s family doesn’t play games together very often, but she agrees that she likes it when they do.

A.’s fourteen year old brother is “addicted” to video games. All he thinks about are games.

A. and her brother play together a lot.
A likes her brother and thinks he is really nice. She says that sometimes he saves her life. She corrects herself saying that he *would* save her life.

A. sometimes draws small pictures. On these she did.

When drawing on her own whether or not she uses a lot of colors depends on what she is drawing.

When drawing on her own A. likes to draw colorful butterflies, flowers and rainbows.

On these drawings A. chose to use all black because she was “working.”

A. agrees that she is smiling in almost all of her pictures and is generally a happy person, her nicknames at home being “Happy Happy” and “Tinkerbell.”

Everyone is smiling in the family portrait [drawing #5] except for A.’s brother who doesn’t want to play and dad who is picking up a piece that fell.

A. agrees that everyone in her family is pretty close the way that she drew them close together in her picture.

A. agrees that in drawing #4 the teddy bear is so close to her eyes that she can’t see the surgery. She focuses on the toy she will get afterwards instead of on the surgery.

It is hard for A. to get IV’s in her hand because they hurt a lot except when she gets a toy.

After a “poke” A. gets a toy.
A.’s hair has grown almost down to her shoulder and is a little bit darker than it was before it fell out.

A. agrees that having cancer has changed her life.

A.’s life has changed in a good way because now she gets toys after she gets a shot or has a scan.

A.’s hair fell out and then it grew back again since she has had cancer.

Having cancer has made A. special.

A. has had lots of attention.

A. likes all of that attention. It makes her feel special.

Losing her hair from chemo made A. different from other kids.

Having cancer has also made A. different from other kids her age because they haven’t been through everything she has like being in the hospital and having scans and surgeries.

A. has had five surgeries.

A. took Zoloft which helped her not be sad.

A. was sad because she didn’t like being sick and being in the hospital.
When A was first diagnosed she didn’t want to say the word “cancer.” So she made up a different word for her family to use: “the horror.”

A. used “the horror” to describe cancer because she says it is evil.

Sometimes A. lets people say “cancer.”

“The horror” was the shortest other word to describe cancer that A. could think of.

A. agrees that “the horror” is a pretty good description of just how awful cancer is.

A. just doesn’t like the word “cancer.”

A. likes saying “the horror” instead of “cancer” because it is evil, but it is funny.

“The horror” is A.’s word.

It sometimes makes people laugh to say “the horror.”

A.’s favorite part of getting toys is playing with them.

A. agrees that it makes her happy that her parents want to do something special for her [getting her a toy] after she has had a shot or a scan.

A. doesn’t usually have something particular that she wants.

A.’s parents show that they love her by letting her pick out a toy.
Alexis has Rhabdomyosarcoma, a cancer of the muscle. She laughingly tells me that she knows the name of the cancer she has but does not know how to spell it. She asks for help spelling, and laughingly corrects her mistakes. Alexis explains that Rhabdomyosarcoma is a type of cancer. Her cancer is a lump [a solid tumor].

As we begin, Alexis informs me that she will be eating and drinking while she “works.” As she draws, she smiles, laughs and explains to me what she is drawing. She completes the entire first drawing in black crayon. When asked if she would like to add any other colors or her picture, she simply says, “no.” Alexis asks if I know what she has drawn. She explains that she drew herself sitting at a desk drawing a picture with her tongue sticking out, something she likes to do while she draws. She thinks this drawing describes her well, doing something she likes to do. Smiling in almost all of her pictures, Alexis later agrees that she is generally a happy person, her nicknames at home being “Happy Happy” and “Tinkerbell.” Alexis further describes herself as someone who likes to ride her bike, swim, play with Barbies and get toys. She also likes to visit Los Angeles, where she was born and where her cousin lives. Alexis says that she does not have a sister, except, she jokes, for her two female pets. Alexis says that she is also an artist and that she has won a drawing contest.

Alexis says that if she were to draw herself in the future, she would draw her and her older cousin doing their nails. She explains her hair fell out and then it grew back again since she has had cancer. Alexis says that if she had drawn herself before she had cancer she would have drawn herself eating – when she is well she eats “lots,” she explains. She doesn’t eat as much when she is sick because she doesn’t like the food in the hospital.
Alexis says that losing her hair from chemo made her “different” from other kids. Having cancer has also made Alexis different from other kids her age because they haven’t been through everything she has like being in the hospital and having scans and surgeries. Alexis has had five surgeries. Alexis says that she was sad because she didn’t like being sick and being in the hospital. She explains that she took Zoloft which helped her “not be sad.”

As she completes the second picture of herself in the clinic, Alexis explains that she is drawing a table and chairs. She explains that for the drawing of herself in the clinic she has drawn herself sitting at the table in the clinic with me. Alexis adds her food, the box of crayons and the tape player. Alexis laughingly notices that she has drawn little pictures on the big pieces of paper. She says that sometimes draws small pictures. She doesn’t know what made her want to draw these small, she says she “just did.” Alexis says that she drew the picture of herself in the clinic so that you could see everything. In describing what it is like to be in the clinic, Alexis says that you get toys a lot. At the hospital there is a gift shop she likes, but, she says, she does not get things from there very often. Alexis adds that everyone at the clinic is nice. She doesn’t like getting poked with a needle in her hand or arm for an IV. Alexis screams a lot when she gets poked by needles in the clinic. It hurts her when they push the needles in and out. Alexis doesn’t like before she gets poked, either. She feels scared as she looks back and forth from the needle to the room. Alexis feels scared when she has to endure painful procedures and when she does not know what to do. Alexis says that she does not like it when doctors make you wait. This morning she had to wait for two and a half hours for her scan. Alexis thinks the worst thing about waiting is that she gets bored. She also does not like the gross smell of the hospital.
Alexis laughs and jokingly whines as she draws the “worst” thing about having cancer. Reminded that she can use any of the crayons, she reasserts that she wants to use black, a color she really likes and even wants as the color of her prom dress. Later Alexis said that when drawing on her own the colors she uses depend on what she is drawing. Alexis often likes to draw colorful butterflies, flowers and rainbows. On these drawings, however, Alexis chose to use all black because she was “working.” She says that the pillow she has drawn looks “like a big stone.” She laughingly admits that the pillows at the hospital are very uncomfortable like stones. Alexis laughs nervously as she draws herself in-between two doctors, one with an IV needle and a surgeon with scissors. She says that the figure with the needle is “evil” because of the way she has drawn his eye. Alexis feels scared in situations like this when she is “trapped” in the middle, not knowing what to do first. In this picture she doesn’t know what to do. She has to have both procedures (get an IV and have surgery) and does not know which to do first.

As she draws the fourth drawing of what helps to get her through the tough times, Alexis laughs and talks about what she is drawing. She includes a pillow that she proudly says looks “more like a pillow” than her previous attempt. She describes this drawing of what helps her get through the tough times, which shows her first surgery, as “violent.” Before her first surgery Alexis felt scared and nervous. She points out that the doctor figure in her drawing has scissors and a knife. She describes the surgery where he will “cut [her] open, stick the tumor into the knife,” and put the tumor on a tray. What helped Alexis get through her first surgery was the promise that she would get a toy once it was over, which she did. She felt happy when she was told she would get a toy after her surgery. She focused on that to get her though the surgery. Alexis can’t think of anything else that helps her to feel better when she is feeling bad or scared except for the
nice doctor who noticed her shoes before her first surgery. She agrees that in this picture the teddy bear is so close to her eyes that she can’t see the surgery. She focuses on the toy she will get afterwards instead of on the surgery underway. It is also hard for Alexis to get IV’s in her hand because they hurt a lot – except, she says, when she gets a toy. Alexis’ favorite part of getting toys is playing with them. Alexis agrees that it makes her happy that her parents want to do something special for her like getting her a toy after she has had a shot or a scan. Alexis doesn’t usually have something particular that she wants. Alexis’s parents show that they love her by letting her pick out a toy.

For her family drawing, Alexis draws a picture of her mother, herself, her brother, and her father playing Monopoly. In the drawing Alexis’ dad doesn’t want to, but is trying to get a piece that fell under the table while her brother smiles because he didn’t have to do it. Out of her family Alexis likes playing games the most. Sometimes when the others will play with her she gets to play. Her family doesn’t play games together very often, but she agrees that she likes it when they do. Alexis and her brother play together a lot. She likes her brother and thinks he is really nice. She first says that he sometimes saves her life, then corrects herself saying that he would save her life. Everyone is smiling in the family portrait except for her brother who doesn’t want to play and dad who is picking up a piece that fell. Alexis agrees that this drawing describes her family pretty well. Alexis agrees that everyone in her family is pretty close the way that she drew them close together in her picture. Alexis points out that all her family [mother and father] are at the clinic except for her older brother who is at school.

Alexis explains that when she was first diagnosed she says that did not want to say the word “cancer.” Instead, Alexis made up a different word for her family to use: “the horror.” Alexis used “the horror” to describe cancer because she says it is evil.
Sometimes Alexis lets people say “cancer.” “The horror” is Alexis’s word. It was the shortest other word to describe cancer that Alexis could think of to describe cancer. Alexis agrees that “the horror” is a pretty good description of just how awful cancer is. Alexis just doesn’t like the word “cancer.” Alexis likes saying “the horror” instead of “cancer” because it is evil, but it is funny. She says that it sometimes makes people laugh to say “the horror.” Alexis agrees that having cancer has changed her life. She adds that her life also has changed in a good way because now she gets toys after she gets a shot or has a scan. Alexis says that having cancer has made her special. Alexis likes that she has had lots of attention – it makes her feel special.
Alexis: Psychological Description

I met Alexis and her parents in the waiting room of the clinic after an appointment. Her parents, both of whom had come to be with Alexis during her appointment, greeted and spoke to doctors and other parents in the waiting room. Alexis sat at a round table with several other children and a child life specialist talking and playing animatedly with a new Barbee doll. She had had a bone scan earlier that morning, for which she was not allowed to eat or drink for the preceding 12 hours. In the waiting room she was happily enjoying a bag of chips and juice, stopping occasionally to offer to share her chips with her parents, one of the other kids in the waiting room, and, after we had been introduced, with me. She sat nestled between her parents, snacking away, as I reviewed the purpose of the study and forms with her and her parents. Her parents stopped several times during my reading of the assent form with Alexis to ask if she understood particular concepts (e.g., privacy) or had any questions. Once we had completed the forms, Alexis packed up her chips and juice and we left her parents while we went to conduct the interview.

Seven-year-old Alexis was first diagnosed with cancer two years ago, at the age of five. She told me the name of her diagnosis, rhabdomyosarcoma, and explained that it is a “lump,” a solid tumor. Even if she has an imperfect or incomplete understanding, Alexis is able to use medical language to interact and exchange information with the adults and medical staff around her. She did not appear to be intimidated by the “big words” used to describe her illness and treatment, nor by the medical staff who she described are “nice.” In fact, at one point in our interview, Alexis saw her doctor and was not shy, but instead teased him for making her wait before her earlier appointment. In her drawings, she drew herself as large as the figures of doctors and surgeons, again revealing that while she very
clearly does not like the procedures, she is not intimidated by being in the hospital nor by interacting with the medical staff. Her ability to use the correct medical terminology and deal confidently with adults garners respect, and may encourage others to view and treat her as more mature.

As I asked Alexis for some basic information, she took the opportunity to show off a bit, providing even more information that I requested. This seemed to hint at her interest and involvement in the project and her desire to show me that she could be a good and helpful participant. Alexis sought guidance from me, the authority figure in this situation, for spelling and for clarification of my questions demonstrating her desire to give the “right” answer. When she made a mistake, she was able to laugh, correct it, and move on. Throughout the interview Alexis laughed, joked, and otherwise worked to maintain a lighthearted conversational air. For example, while she drew she continued to smile and talk to me about what she was drawing. This move in particular served to keep me as researcher connected, involved and smiling along with her, while at the same time providing her with some emotional distance in this strange new interaction.

The playful openness and good humor that I witnessed in Alexis’ engagement with me and with the other adults and children in the waiting room was starkly contrasted by the world that emerged through her drawings. Though she happily chatted and smiled while drawing, her drawings were monochromatic - everything drawn in black. I was so taken aback by the lack of color in her drawings that I wondered if I had not made it clear that she was free to use all the crayons and broke with my script to remind her that she could use any of the colors in her drawings. Despite my interference, Alexis reasserted that she only wanted to use black, driving the point home by saying that she really likes black, her “prom dress is going to be black.” Later Alexis said that when drawing on her
own she uses different colors depending on what she is drawing. She said that she often likes to draw colorful butterflies, flowers and rainbows. In the drawings for our interview, however, Alexis chose to use all black because, she said, she was “working.”

For her self portrait, Alexis chose to draw herself drawing. She laughed and agreed as I noted it was an “up to the minute self portrait.” She described herself as someone who likes to draw, a prize-winning artist, who has a sense of humor (demonstrated, in part, by her tongue sticking out in this drawing). She went on to say that she enjoys biking, swimming, playing with Barbees and getting toys. These are ordinary activities for a child her age. Her continued interest in these activities may serve to help her maintain a sense of normalcy in the face of her illness and treatment. In using these activities to describe herself, she identifies herself as a “normal” child. She may have cancer and have to endure needle sticks and surgery, but she likes toys and activities like any other girl her age. When asked to describe how she might draw herself in the future, Alexis says she would draw herself painting her nails with her cousin. Here she describes another ordinary, fun, activity she might engage in as a teenager, again emphasizing how she wants to go on with her life and enjoy the little ordinary things that other girls enjoy (e.g., painting her nails, looking pretty, hanging out with a friend).

When pressed to about whether anything has changed since she has had cancer, Alexis says that she lost her hair, had had bone scans, been in the hospital, and had five surgeries. She listed these things rather matter of factly, not stopping to elaborate on what these experiences had been like for her. She simply lists them off as things she has done that others have not. She felt that these experiences made her different from other children her age who have not had cancer. She also mentioned that when she is well, she eats “lots.” When she is sick and in the hospital, she does not eat, either because she has
no appetite or because, as she said, she does not like the hospital food. When she cannot
or does not eat, she may lose weight, and have less energy, exacerbating the symptoms
she already feels when sick.

In the second drawing, Alexis again drew herself drawing. As in her first picture,
she drew a picture of the her that I could see, as if to say, “You want to see me? Just
look. I’m right in front of you.” For this second drawing, I had asked Alexis to draw a
picture of herself in the clinic or hospital. In response, she focused on the immediate
environment of the table and chairs in the clinic where we sat during the interview. As I
asked her about her drawing, Alexis laughed, saying that she drew this picture so that
“you could see everything.”

Though she drew “everything” on the table, she drew nothing of the examining
rooms, doctors, or even the friendly environment of the waiting room in this narrowly
focused perspective. Alexis has distanced herself from the surrounding environment and
procedures of the clinic. In fact, Alexis’ own face and expressions are hidden from view
in this drawing. Seen from overhead and looking away, we are hardly able to see Alexis in
the clinic at all. We cannot see a smile or a frown. All that we know is that she sits and
she draws. By drawing herself from above and facing away, she is also distanced from
seeing herself and her own emotional connection to being in the clinic. Alexis may have
this response as a general means of avoiding or distancing herself from feelings of anxiety
or fear associated with the clinic, or she may have simply not been ready to enter into
that emotionally-charged field with someone she had only just met.

In her description of the clinic, Alexis continued to distance herself from the
negative aspects of her experience, at first speaking only of the positive and mundane: the
nice people in the clinic, the gift shop, and the toys she might receive after a visit to the
Alexis said that she does not like getting poked with a needle in her hand or arm for an IV. Alexis screams a lot when she gets poked by needles in the clinic. It hurts her when “they push the needles in and out and in and out.” Alexis doesn’t like before she gets poked, either. She described feeling scared as she looks back and forth from the needle to the room. Alexis feels scared when she has to endure painful procedures and when she does not know what to do. Alexis added that she does not like it when doctors “keep you waiting.” This morning she had to wait for two and a half hours for her scan. Alexis thinks the worst thing about waiting is that she gets bored. Waiting also likely plays out the “scary” cycle of anticipation in which Alexis knows the painful thing that is coming but has to wait for it to happen. She also does not like the gross smell of the hospital. The hospital is uncomfortable (i.e., pillows like “stones”), unfamiliar (she does not like the food, the smell is “gross”), and menacing as the place where painful procedures occur.

Although she did not know me, Alexis was able to assert her own opinions and desires during the interview. Before we began, she told me that she was ready to “work,” and informed me that she would be eating and drinking during the interview. Asked if she would like to use colors other than black in her drawings, she held fast, letting me know that it was her choice. Alexis was clear and vocal about what she doesn’t like about the hospital (i.e., needles, the food, waiting). Alexis did not seem intimidated by the medical / professional / adult atmosphere of the hospital. When not anticipating or getting a painful procedure, Alexis seemed at ease. After two years, she knows what to expect from her visits to the clinic and when it is safe to let her guard down.

Alexis laughed and jokingly whined as she drew the “worst” thing about having
cancer. Again, Alexis appeared to use humor as a means of diffusing and distancing herself from a difficult situation, or in this case memory. She said that the pillow she has drawn looks “like a big stone.” She laughingly admits that the pillows at the hospital are very uncomfortable like stones. Alexis laughed nervously as she drew herself in-between two doctors, one with an IV needle and a surgeon with scissors. She described the figure with the needle is “evil” because of the way she drew his eye. In this picture, she said, she doesn’t know what to do. When I asked Alexis how she feels in these kind of situations, she described feeling scared when she is “trapped” in the middle not knowing what to do first. She has to have both procedures (get an IV and have surgery) and does not know which to do first.

Alexis often laughed and joked with me during the interview. In many cases she laughed while speaking of or drawing a difficult, painful, or otherwise emotional aspect of living with cancer. For example, she laughed and made whimpering noises while drawing the “worst” thing about having cancer. This trend indicates that Alexis uses humor as a means to diffuse such emotionally laden or negative situations. When she is able to laugh she is able to maintain some emotional distance from what otherwise might cause her to feel anxious or frightened. In this situation, at least, it served to help her maintain distance and composure while involved in the interview with me, a person she did not know very well. Along these lines, Alexis’ mother had relayed to me that when she was first diagnosed, Alexis did not want her family to use the word “cancer.” This at first appeared to be a form of denial (“if we don’t talk about it, it won’t be true”), yet as Alexis went on to tell me, she asked them to call her cancer “the horror” instead – a rather unlikely euphemism. In talking to me, Alexis always spoke the phrase “the horror” in a melodramatic tone of voice. Alexis was not denying that she had cancer, but by using her
sense of humor, she was able to distance herself and others from the powerful negative emotions associated with the word "cancer." In doing so, Alexis could still talk about her "awful" experience of cancer while diffusing the situation and allowing herself and others to face them with a smile.

As she drew the fourth drawing of what helps to get her through the tough times, Alexis talked to me about what she was drawing. She included a pillow that she proudly said looks "more like a pillow" than her previous attempt. For most of my participants, this drawing of "what helps you get through the tough times" tended to be one of the most happy, optimistic drawings. Here, however, Alexis drew what helped her in the very midst of a specific "tough time:" her first surgery. Indeed, she described this drawing as "violent." Alexis described feeling scared and nervous before her first surgery. She pointed out that the doctor figure in her drawing has a knife and scissors (something Alexis associates with the medical-surgical lingo of "cutting"). She described the surgery where he would "cut [her] open, stick the tumor into the knife," and put the tumor on a tray. Alexis explained that what helped her get through her first surgery was the promise that she would get a toy once it was over, which she did. She felt happy when she was told she would get a toy after her surgery. She focused on that to get her though. She agreed that in this picture the teddy bear is so close to her eyes that she can’t see the surgery. She focused on the toy she would get afterward instead of on the surgery underway. Here the image of the teddy bear stands out amidst the doctor and medical equipment. It is a figure from the "normal" world of childhood, very out of place in this sterile medical environment. Alexis added that it is also hard to get IV’s in her hand because they hurt a lot – except, she continued, when she gets a toy. Focusing her whole imagination on getting a treat, a toy, and playing with it just as she might have done or
might someday do when she is no longer in treatment, helps Alexis get through the anxiety, fear and pain of surgery and other painful procedures. Alexis agreed that it makes her happy that her parents want to do something special for her like getting her a toy after she has had a shot or a scan. She does not usually have something in particular that she wants. Instead, Alexis said, “They love me - I get to pick it!” Alexis’s parents show that they love her by letting her pick out a toy. In this way, receiving a toy is receiving a token of her parent’s love and care – an acknowledgment from them that she made it through a frightening and painful procedure.

For her family drawing, Alexis drew a picture of her mother, herself, her brother, and her father playing Monopoly. Alexis said that in this drawing her dad does not want to, but is trying to get a piece that fell under the table while her brother smiles because he didn’t have to get it. Of all of her family members, Alexis says that she likes playing games the most. Sometimes when the others will play with her she gets to play. Her family doesn’t play games together very often, but she agrees that she likes it when they do. She enjoys bringing the whole family together to do something fun that she enjoys. Alexis says that she and her brother play together a lot. She likes her brother and thinks he is really nice. She first says that he sometimes saves her life, then corrects herself saying that he would save her life. In this picture, Alexis and her mother have particularly big smiles. Alexis agrees that everyone in her family is pretty close the way that she drew them close together in her picture. Alexis proudly pointed out that both her mother and father were there at the clinic, supporting her. Alexis agrees that having cancer has changed her life. She explained that her life has changed “in a good way” because now she gets toys after she gets a shot or has a scan. Alexis added that having cancer has made her special. Alexis explains that since she has had cancer she has had “a lot of attention”
which has made her feel “special.” Alexis likes that she has had lots of attention. The fact that she said having the attention made her feel special may indicate that she did not feel (or does not remember feeling) as special or that she had as much attention before she had cancer. Given that Alexis now seems to associate gifts with attention and love, she may need extra reassurance that she is still loved and special when she comes off of her treatments.
Appendix B

Junie
[Chose her pseudonym, Junie B. Jones, after a favorite children’s fictional book character. Junie is an 8 year old hispanic female diagnosed with acute lymphoblastic leukemia (ALL) 2 years prior to this interview.]

1. Kristy: It’s September 17. This is Kristy and I’m here with Junie [all names and identifying information have been changed to protect confidentiality]. Would you like to say hello?


3. [tape recorder turned off and rewound to let J. hear her voice]

4. K: Ok. So again, I’m going to ask you some questions and have you do some drawings about what it is like having cancer. If you have a question you can stop and ask me any time. Your mom is right outside if you need her for anything and we can also call T. from child life if you’d like to talk to her. If you need to take a break or just stop we can do that any time, ok?

5. B: Ok.

6. K: Ok. This first page will help me get a little bit of information about you. You can use this pen and just fill in the blanks. First you can fill in how old you are.

7. [J writes in “8”]

8. K: Great. Now you can fill in how old you were when you found out you had cancer, or how many months or years ago that was.

9. J: um... six [writing “6”].

10. K: “The kind of cancer I have is called...” Do you know the name of your cancer?

11. J: Leukemia. How do you write it?

12. K: l-e-u-k-e-m-i-a. ... Ok. “That means...” If one of your friends asked you what it means to have leukemia what would you tell them?

13. J: um...
14. K: Or how did someone explain it to you?

15. J: Cancer in the blood?


17. J: How do you spell cancer?

18. K: c-a-n-c-e-r

19. J: How do you spell blood?

20. K: b-l-o-o-d ... Ok. Let me take that and I will trade you for some crayons [taking crayons out of box]. I’m going to have you do five pictures all together. You can do them any way you want and use any colors you want. And like I said, this is all about your experience of what it has been like to have cancer. So there are no wrong answers and you can do it any way you want. Ok?


22. K: The first thing I’d like you to do is draw a picture of yourself.

23. J: [drawing] [coughing]

24. K: Let me know if you need a drink of water or anything, ok?

25. J: Ok. [drawing... 5 minutes total] Ok. I’m done.


27. J: It’s just me.

28. K: And you drew this nice bright shirt.


30. K: You like purple. Ok. Anything else you can tell me about this drawing?

31. J: [shrugging shoulders]
32. K: Ok. Can you tell me a little about yourself? How would you describe yourself?

33. J: I have three pets.

34. K: Three pets?


36. K: Do you like animals?


38. K: What else would describe you?


40. K: You like to read?


42. K: What kind of books do you like to read?

43. J: [shrugging shoulders] I don’t know. Chapter books.

44. K: Chapter books? Ok. Is there anything else that describes you? Anything about your personality or anything else you like to do?

45. J: I like to sing.

46. K: You like to sing?

47. J: Yea...

48. K: Ok. Is there anything that doesn’t describe you or anything you don’t like to do?

49. J: um...

50. K: That’s a hard question, huh? Can you think of anything?
51. J: um... [shrugging shoulders]

52. K: Ok. That’s all right. Is there anything that you would change about your picture or that would describe you differently before you had cancer?

53. J: um... I had longer hair.

54. K: Longer hair? Did you have really long hair?

55. J: I had it really long, but I cut it before I got sick.

56. K: Ok. Was it straight or curly?


58. K: Do you think it will be straight again?

59. J: [smiling] I don’t know.

60. K: Sometimes it changes, huh?


62. K: Anything else that was different before you had cancer?

63. J: I didn’t have a lot of bruises.

64. K: Bruises? From needles and IVs?


66. K: Is there anything else about you that has changed since you’ve had cancer?

67. J: um... It’s made me braver.

68. K: It made you braver?


70. K: Can you tell me about that?
71. J: um... I don’t know.

72. K: You feel braver about what you’ve been through?


74. K: You’re braver about your treatments and having cancer?

75. J: It still makes me nervous when I think about going but I’m more used to it now.

76. K: You’re more used to it now. Ok. Do you think you’re more brave about other things now, too?


78. K: A little? Ok. What about in the future? Is there anything that would change or be different about you?

79. J: um... [shrugs shoulders]

80. K: You can’t think of anything?

81. J: [shakes head] No. [talking from behind her sweater sleeve]

82. K: Ok. For drawing number two I want you to draw a picture of yourself in the clinic or the hospital.

83. J: [drawing] Can I draw it this way? [turning paper]


85. J: [drawing... 4 minutes total] All done.

86. K: Ok. Can you tell me a little about your drawing?

87. J: This is me sitting on the little thing that you sit on when you get a check up.

88. K: So this is you in for a check up?

89. J: uh huh.
90. K: What else can you tell me about it?

91. J: This is the chairs that are in there.

92. K: And are you waiting for your check up?


94. K: If you’re in the clinic waiting for a check up and you’re sitting on the table how do you feel while you’re waiting for them to come in?

95. J: Sometimes I feel scared and sometimes I feel... not so scared?

96. K: Do you know what makes a difference in the times that you feel scared or not so scared?

97. J: um... Whenever I get a back shot that makes me scared.

98. K: Sure. Can you tell me what that’s like?

99. J: um... It just like... hurts a lot.

100. K: What do you do when you get one of those back shots?

101. J: They give me some sleepy medicine.

102. K: Does that help?


104. K: Anything else that you do or you think about?

105. J: No. I just go to sleep.

106. K: Ok. Can you tell me a little about the clinic?

107. J: The people are nice. Sometimes you get a finger poke. And... I don’t know.

108. K: Do you usually know ahead of time when you’re going to get a finger poke?

109. J: You get it most every day.
K: Ok. Is it different when you have to stay in the hospital?

J: um... I don’t know.

K: What do you like or what do you not like about the hospital?

J: I like the playroom.

K: What do you like about the playroom?

J: Making arts and crafts.

K: Ok. You like to make arts and crafts?

J: uh huh. [smiling]

K: Ok. What do you not like?

J: Staying in the room.

K: Staying in the room?

J: yea... It’s boring.

K: It’s boring?

J: yea.

K: Ok. Now I want you to draw what you think is the worst thing about having cancer.

J: How do I draw it?

K: Well, what is one of the worst things?

J: The needles.

K: The needles? Ok. You can draw the needles any way you want.

J: And having to stay at the hospital.
130. K: And staying at the hospital?


132. K: What is it about staying at the hospital?

133. J: You feel sick and you have to be here.

134. K: You’re sick and you’re here? Away from home?


136. K: Well, you could draw both of those things. You can make a drawing about needles and staying in the hospital. You can draw it any way you like.

137. J: Ok. [drawing... realizes there is not enough room for the second figure] There’s not enough room. [laughing]

138. K: [laughing]

139. J: [drawing... 6 minutes total] All done.

140. K: All done? Ok. Can you tell me about your picture?

141. J: The nurse is coming in with a needle.

142. K: She’s coming with a needle?

143. J: Yea. And I’m watching TV.

144. K: And you’re watching tv?


146. K: Can you think about a time like this when you were in the hospital? What is that like?

147. J: Lying down a lot.

148. K: Lying down a lot?

150. K: I notice it’s just you and the nurse in this picture. Do you spend a lot of time by yourself when you’re in the hospital.


152. K: Sometimes?


154. K: And sometimes you have visitors?


156. K: Not a lot? Who comes to see you?

157. J: My mom and my family sometimes. She stays with me.

158. K: Your mom stays with you?


160. K: Do you like that when she comes to stay with you.

161. J: Yea. [smiling]

162. K: Ok. Tell me about the needles.

163. J: They hurt.

164. K: They hurt when you get a shot?

165. J: Yea...

166. K: Yea. You mentioned before that you get bruises from the needles.


168. K: You don’t like that? Does it remind you of getting a shot? Or do people notice them?
169. J: It reminds me and sometimes it hurts, too.

170. K: The bruises still hurt?


172. K: In the hospital bed here are you in your clothes or in the hospital gown?


174. K: Ok. I thought that didn’t look like the regular hospital gown.


176. K: Ok. For this next picture I want you to draw what has helped you get through the tough times.


179. J: [drawing... 5 minutes] Ok.

180. K: So this is your mom?


182. K: Ok. And what is she doing in this picture?

183. J: um... I want to add some things.


185. J: [drawing second figure... 3 minutes] Ok.

186. K: Ok. What did you add here?


188. K: You added you?

190. K: Ok. So what is going on in this picture?

191. J: We’re going to hug each other.

192. K: You’re going to hug each other? Ok. And you both have big smiles here.


194. K: And what’s on your mom’s shirt here?


198. K: Ok. So tell me how you mom helps you.

199. J: She holds my hand.

200. K: She holds your hand.

201. J: And she sits beside me. She makes me feel better.

202. K: What does she do or say that makes you feel better?

203. J: When she holds my hand that makes me feel better.

204. K: It makes you feel better when she’s there holding your hand?


206. K: Anything else that you can think of?

207. J: um... Not really.

208. K: Ok. This is our last picture. I want you to draw your whole family with everyone doing something.
K: [drawing]  

210. [mom comes in]  

211. Mom: [kisses J. on head]  How’s everything going?  

212. J:  Fine.  [smiling]  

213. K:  She’s doing great.  We’re on our last drawing.  

214. M:  Ok.  I’ll see you soon, ok?  

215. J:  Ok.  [smiling]  

216. [mom leaves]  

217. J:  [drawing... 5 minutes total]  Ok.  These are my dogs.  [smiling]  

218. K:  Your dogs?  They’re part of the family, too, huh?  


220. K:  Ok.  Great.  What are your dogs’ names?  

221. J:  Maggie and Buddy.  

222. K:  Maggie and Buddy.  Ok.  So tell me what’s going on in your drawing.  

223. J:  We’re calling the dogs.  

224. K:  You’re all calling the dogs together?  


226. K:  This is you and mom and dad?  


228. K:  And what are you going to do?  

229. J:  Go play with the dogs.
230. K: Play with the dogs. Do you like to play with your dogs?

231. J: Yea. [smiling]

232. K: Ok. Can you describe your family for me?

233. J: um... Like how?

234. K: What are they like? What kind of things do they do?

235. J: We like to watch movies together. We go to the movies and go bowling.

236. K: Ok. How would you describe your mom and dad?


K: He likes computers and music?

J: And mom likes to go to my grandmas.

K: Does your grandma live close by?

J: Yea.

K: Does this drawing describe your family pretty well?

J: Yea.

K: Ok. We’re about done here. I want to look over your drawings for just a minute together. I can tell you some of the things that I noticed and you can tell me if what I say sounds right to you or if it’s different for you. Ok?


246. K: Ok. One of the first things I noticed was that your drawings are a good size here on the page. You used as much space as you needed.
247. J: Yea. [smiling]

248. K: Some kids draw pictures of themselves that are really small, especially if they are feeling shy. I noticed that you didn’t really do that. Do you think of yourself as a shy person or just maybe with people you don’t know?

249. J: At first I’m kinda shy.

250. K: At first? Ok. You seemed a little shy and quiet with me at first, but your drawings don’t look like you’re always a shy person. You drew yourself nice and big in the middle of the page here [drawing #1]. Sometimes people draw themselves small or off in the corner. That made me think you weren’t always so shy.

251. J: Yea. [smiling]

252. K: Ok. One of the things I noticed in this drawing is that there aren’t any other people with you [drawing #2]. I wondered if sometimes when you’re in the clinic you feel a little isolated or lonely? Do you ever feel that way?

253. J: um... Not really.

254. K: Not really?

255. J: My mom’s always with me.

256. K: Your mom is with you. Ok. The other thing I thought from this picture that you drew was that there weren’t any people, like your mom, but that means there also aren’t any doctors or nurses coming at you with needles.

257. J: Yea. [laughing]

258. K: So I wondered if you were thinking about what it is like in the clinic without thinking about the needles and the not so good things that happen there.


260. K: Does that sound more right?

261. J: Yea. [smiling and nodding]
262. K: Ok. In these first three drawings you went from standing to sitting to lying down. I know that when you’re waiting for an exam you have to sit on the table, and you lie down in the bed in the hospital. It also reminds me of when you start feeling bad and you have to start sitting down or lying down because you’re tired or you don’t feel good.


264. K: Yea? And when that happens things like needle shots happen to you instead of you going out and doing the things you want to get up and do.


266. K: Ok. In this drawing the nurse here is one of the only people that you didn’t draw with a smile [drawing #3].

268. K: She’s got a needle?

270. K: Ok. This is a great picture of you and your mom. I like how your arms are outstretched about to hug. And your mom’s arms were like that even before you added yourself here. Was she going to be hugging you anyway and then you decided to add yourself?

271. J: Yea. [smiling]

272. K: I thought so. So having your mom and your family close to you and supporting you is a big part of what helps you get through all this, huh?


274. K: Do you have friends or other family members that help you?

276. K: Your dad?


278. K: Does he do anything different from your mom that helps you? Or kind of the same things?

279. J: The same things.

280. K: The same things? Ok. In this picture you all have your arms outstretched, too [drawing #5]. It reminded me of that game where someone stands behind you and when you fall back they catch you. Have you ever seen that or played that game?

281. J: I haven’t played it, but I know.

282. K: This picture made me think about that game. You’re all together and calling the dogs and focused on them, but you’re all standing behind each other like you could catch each other.

283. J: Yea. [smiling]

284. K: Ok. How did you feel about doing these drawings and talking about them?


286. K: Fine?


288. K: Ok. Do you have any questions for me?


290. K: No questions?


292. K: Well, that’s all I think I have for you. Thank you so much.
Figure A.4, detail: Alexis’ drawing of what gets her through the tough times.
Kristy Novinski  241  Children’s Experience of Cancer

B3
Drawing Analysis Worksheet

**Name:** Junie  
**Age:** 8  
**Drawing #** 1  
**Time:** 5 minutes

Bright, happy, confident, well-proportioned. Drawing appears much more expansive and outgoing (less shy) than J. does during beginning of interview. Using full range of colors and space.

**Position of Self:** Standing upright – independent

**Action:** standing (arms indicate movement); Shows life & potential movement

**Size and Proportion**
- **Self:** Tall figure. Appropriate to picture, well proportioned
- **Other human figures:** n/a
- **Non human figures:** n/a

**Spatial Relationships**
- **Human figures:** n/a
- **Non human figures:** n/a

**Facing:** Facing outward

**Facial Expressions:** soft smile. positive, happy

**Eyes:** slightly large (emphasized with lashes); piercing pupils – aware of environment / vigilant

**Use of Color:** 5 colors used. Purple & red shirt prominent. Bright – good sense of self & well being

**Use of Paper:** 50-75% of available space. Large depiction of self. Confident. Not intimidated by space.

**Placement on Paper:** Centered on page – less anxious.

**Emphasis/Exaggeration/Omission of Body Parts:** n/a

**Presence/Absence of Medical Instruments:** none
Turned paper horizontally after beginning. Willing & able to manipulate environment to achieve best outcome. Still bright, happy. Alone in exam room, but stool signifies others who will come. Figure looks at ease (for being in the clinic)

**Position of Self:** Sitting on examination table in clinic. Supported, more dependent / passive position.

**Action:** Sitting on examination table waiting for dr or nurse. Potential for movement. More dependent / passive stance. Waiting on exam & what will be done to her.

**Size and Proportion:** Self figure well proportioned. realistic in relation to bed and stool.

**Spatial Relationships:** Sitting on table. stool nearby for dr or nurse when they arrive. functional. Reveals relationship between self and staff – patient waits on experts who will operate on her

**Facing:** outward

**Facial Expressions:** smiling. Positive and calm. Procedure hasn’t begun yet?

**Eyes:** Pupils, slightly large – looking out.

**Use of Color:** 5 colors used. Self – colorful. Bed & stool in black (more serious / anxiety-provoking?)

**Use of Paper:** 50%

**Placement on Paper:** Centered. near bottom of page – insecure or becoming reality grounded

**Presence/Absence of Medical Instruments:** bed and stool. No other instruments of the clinic.

**Emphasis/Exaggeration/Omission of Body Parts:** ears (new acquisition at this age, but present in #1 and omitted here) not hearing... noises of the clinic, other patients... crying?
Drawing Analysis Worksheet

Name: Junie  Age: 8  Drawing # 3  Time: 4 minutes

Still bright, though slightly more subdued. Self even more reclined / passive. Kept going even though out of space (accidental transparency) – determined. TV – trying to distract self from what is coming (needle with shot). (Though depicted as a patient, wearing her own clothes. Individuality / self-directed / not totally identifying with role of patient)

Position of Self: Reclining in bed. (could be increased anxiety, also realistic that she would be in bed while in hospital) most dependent/passive stance yet.

Size and Proportion: Self figure well proportioned. Other human figures slightly larger than self figure (realistic) _Non human figures: bed, tv, shot – functional, well proportioned

Spatial Relationships: Distant to other human figure, but with gap closing. Self & nurse’s arms extended. (self reaching out or blocking?)

Facing: Profiles. Self & nurse facing one another (though self oriented towards tv distraction)
Facial Expressions: self – neutral expression; nurse – drawn, but difficult to make out – not menacing, but not comforting
Eyes: With pupils – watching.

Use of Color: 5 colors. Still colorful, though more black (could indicate anxiety / loss of control)

Use of Paper: 50-75% Large self & nurse figure. Not intimidated by space.

Placement on Paper: centered at bottom of page, seeking grounding (anxious or seeing to e reality-oriented – down to earth)

Presence/Absence of Medical Instruments: Bed, needle. well proportioned

Emphasis/Exaggeration/Omission of Body Parts: ears – new acquisition at this age, but were present in #1. Isolated, not hearing (other patients, words of comfort from nurse?)
Name: Junie  Age: 8  Drawing # 4  Time: 7 minutes


Position of Self: standing upright

Action: Self reaching out to hug mother, mother reaching out to hug J.

Size and Proportion
  Self: medium in relation to self figure in other drawings; well proportioned; realistically smaller than mother figure
  Other human figures: well proportioned. Larger than self figure

Spatial Relationships: Close but not touching – about to hug

Facing: profiles. Self & mother figures facing one another.

Facial Expressions: Self & mother figures smiling.

Eyes: well proportioned with pupils; self & mother looking at one another

Use of Color: 6 colors used. Wide, energetic palette

Use of Paper: 40%

Placement on Paper: Centered on (slightly lower) left side. (Klepsch & Logie, 1982, left-sided suggests past orientation; bottom – insecurity or reality-oriented)

Presence/Absence of Medical Instruments: none

Emphasis/Exaggeration/Omission of Body Parts: ears on self and mother figure (new acquisition at this age, but present in #1 and omitted here) not hearing / listening...? Doesn’t seem consistent
Family engaged in common activity – calling the dogs. Getting ready to play with the
dogs. Playful, nurturing (caring for pets / extended family), cohesive family. “Standing
behind” one another literally & figuratively. J. looking forward to dogs, can’t see mom &
dad, but knows they are behind her / engaged in this activity with her. Arms extended in
calling dogs, but also reaching out to / supporting other family members (dad to mom,
mom to J, J to dogs). Cohesive family unit

**Position of Self:** standing upright (independent posture)

**Action:** All three human figures (J & parents) calling the family dogs to come and play

**Size and Proportion:** Self and parental figures fairly large and well (realistically)
proportioned. Dad largest, then mom, then J. (then dogs). All clothed – individuality
(different colored shirts) Well drawn dogs (perhaps a common subject of J’s drawings)

**Spatial Relationships:** Family all very close but not touching (Dad touching back of
mom). Supportive posture with arms extended towards one another even as looking
ahead to mutual project

**Facing:** All figures facing dogs, away from one another towards common center of
attention

**Facial Expressions:** All smiling. Positive family environment.

**Eyes:** Well proportioned with pupils. Looking ahead.

**Use of Color:** 6 colors used. Bright, happy, energetic use of color.

**Use of Paper:** 80% Not shy about using available space.

**Placement on Paper:** Centered, feet on bottom baseline (realistic / grounded)

**Emphasis/Exaggeration/Deemphasis/Omission of Body Parts:** ears on self and mother &
father figures (new acquisition at this age, but present in #1 and omitted here) not hearing
/ listening...? Doesn’t seem consistent with insecurity or inadequacy related to this part
or block.
Junie: Meaning Unit Analysis

*Demarcation of Meaning Units*

1. **Paragraphs 6-9**
   J. is 8 years old. She was 6 when she was first diagnosed.

2. **Paragraphs 10-19**
   J. has leukemia, a cancer in the blood.

3. **Paragraphs 11-12, 17-20**
   J. asks for help spelling “leukemia,” “cancer” and “blood.”

4. **Paragraphs 24-26**
   J. coughs, and agrees she will asks for help if she needs a drink of water or anything.

5. **Paragraphs 26-31**
   J. says of her drawing, “It’s just me.” J. drew herself in a purple shirt. She likes purple.

6. **Paragraphs 32-37**
   J. has three pets – two dogs and a fish. She likes animals.

7. **Paragraphs 38-43**
   J. likes to read chapter books.

8. **Paragraphs 44-47**
   J. also likes to sing.

9. **Paragraphs 48-51**
   J. cannot think of anything that doesn’t describe her or that she doesn’t like to do right now.

10. **Paragraphs 52-61**
    Before she had cancer J. had longer hair. It was really long, but she cut it before she got sick. It was straight, but J. does not know if it will be straight when it grows back.

11. **Paragraphs 62-65**
    Before she had cancer J. didn’t have a lot of bruises [from needles and IVs].
Having cancer has made J. braver. It still makes her nervous when she thinks about going [to the clinic or hospital], but she is more used to it now. She agrees that she is more brave about other things now, too.

Right now J. cannot think of anything that would be different about her in the future.

J. asks if she can turn the paper horizontally for her drawing.

J. describes her drawing of her sitting on the [exam room bed] for a check up.

Beside the bed she has drawn a chair [stool] like those in the exam rooms.

In her drawing J. is waiting for a check up.

When she is in a room waiting for a check up, as she is in her drawing, J. sometimes feels scared and sometimes feels not so scared.

Getting a back shot [a spinal tap or bone marrow aspiration] makes J. feel scared. [She feels not so scared when she does not get a back shot.]

Getting a back shot hurts a lot.

When she gets a back shot they give her some sleepy medicine and she goes to sleep.

The people at the clinic are nice.

Sometimes at the clinic you get a finger poke.
Paragraphs 108-109
You get a finger poke most every day at the clinic.

Paragraphs 110-117
J. likes the playroom at the hospital. She likes making arts and crafts while she is in the hospital.

Paragraphs 118-123
J. does not like staying in the room at the hospital. It’s boring.

Paragraphs 124-128
J. asks how to draw the worst thing about having cancer.

Paragraphs 126-128
J. thinks that the needles are one of the worst things about having cancer.

Paragraphs 129-136
J. thinks that having to stay at the hospital is also one of the worst things about having cancer. She does not like feeling sick and having to be in the hospital and away from home.

Paragraphs 137-138
J. laughs when she realizes she has not left enough room for the second [nurse] figure in her drawing. She draws the figure anyway, allowing the nurse to overlap the television.

Paragraphs 140-145
J. explains that she drew the nurse coming in with a needle while J. is watching TV.

Paragraphs 146-149
J. says that in the hospital she is lying down a lot.

Paragraphs 150-153
J. is sometimes by herself in the hospital.

Paragraphs 154-155
Sometimes she has visitors, but not a lot.

Paragraphs 156-157
J’s family sometimes comes to see her in the hospital.
Paragraphs 157-161
Her mom stays with her in the hospital, which she likes.

Paragraphs 162-165
Needles hurt.

Paragraphs 166-171
J. doesn’t like getting bruises from the needles. The bruises remind her of getting the shot and sometimes hurt, too.

Paragraphs 172-175
J. has drawn herself in the hospital bed wearing her own pajamas, not a hospital gown.

Paragraphs 176-181
J. draws her mom who has helped her get through the tough times.

Paragraphs 182-189
J. adds herself to the picture with her mother.

Paragraphs 190-193
In her drawing, J. and her mother are going to hug each other.

Paragraphs 194-197
J. has drawn a heart on her mother’s shirt just like the heart she drew on her own shirt [in this and other drawings].

Paragraphs 198-205
[To help her get through the tough times,] J.’s mom holds her hand and sits beside J. Her mom makes J. feel better. When she holds J’s hand that makes J. feel better.

Paragraphs 206-207
Right now J. cannot think of anything else that helps her get through the tough times.

46  Paragraphs 208-209
J. begins drawing the last picture.

47  Paragraphs 210-216
J.’s mom comes in, gives J. a kiss on the head and asks how everything is going. She tells J. she will see her soon and leaves.

48  Paragraphs 217-227
J. draws herself, her mom and dad calling their two dogs.

49  Paragraphs 228-231
In the drawing J. and her family are going to go play with the dogs, which she likes.

50  Paragraphs 232-233
J. asks me to clarify how I want her to describe her family.

51  Paragraphs 234-235
J.’s family likes to watch movies together. They go to the movies.

52  Paragraph 235
J.’s family goes bowling.

53  Paragraphs 236-238
J. describes her dad by saying that he likes computers and music.

54  Paragraphs 239-241
J. describes her mom by saying that she likes to visit J’s grandma who lives close by.

55  Paragraphs 242-243
J. thinks that this drawing describes her family pretty well.

56  Paragraphs 244-245
J. agrees to listen to my initial thoughts about her drawings and tell me if they are or are not accurate.
J. smiles and agrees when I say that I noticed she used as much space as she needed for her drawings.

J. is kind of shy when she first meets people.

J. smiles and agrees that she isn’t always as shy or quiet as she was during the interview.

J. disagrees with me, saying that she does not really feel isolated or lonely in the clinic because her mom is always with her.

J. laughs and agrees that although there aren’t any people in her clinic drawing that also means that there aren’t any doctors or nurses coming at her with needles.

J. smiles and agrees that it is more accurate to say that for her drawing she thought about what it is like in the clinic without thinking about the needles and the not so good things that happen there.

J. agrees that standing, sitting and lying down in her drawings is like when she starts feeling bad and has to start sitting or lying down because she is tired and doesn’t feel good. She agrees that when that happens, things like shots happen to her instead of her going out and doing the things she wants to get up and do.

In drawing #3, J. drew the nurse without a smile. She has a needle.

In drawing #2, J. drew her mother with arms outstretched to hug her even before she decided to add herself to the drawing.

J. agrees that having her mom and her family close to her and supporting her is a
big part of what helps her.

67  Paragraphs 274-279
J.’s dad also helps her by doing the same things as her mom [holding her hand, sitting beside her].

68  Paragraphs 280-283
J. knows of the game I am reminded of by her fifth drawing in which you fall back into the arms of someone standing behind you.

69  Paragraphs 284-292
The interview ends with J. feeling fine with no questions for me.
Junie is eight years old. She was six when she was first diagnosed with acute lymphoblastic leukemia (ALL). Junie explains that leukemia is a cancer in the blood.

Junie describes her first drawing, a self portrait, saying “it’s just me.” She drew herself in a purple shirt because she likes purple. When asked to describe herself, Junie says that she likes animals and has three pets – two dogs and a fish. She also likes to read chapter books and sing. Later, Junie smiles and agrees that she used as much space as she needed for her drawings. Junie says that she is kind of shy when she first meets people, but she smiles and agrees that her drawings are not small and shy and that she isn’t always as shy or quiet as she was during our interview.

Junie says that before she had cancer she had longer hair. She explains that it was really long, but she cut it before she got sick. Her hair was straight, but Junie does not know if it will be straight when it grows back. Before she had cancer Junie also explains that she did not have a lot of bruises from needles and IVs. When asked what, if anything, might be different about her in the future, Junie said she could not think of anything.

Junie describes the second drawing of her in the clinic sitting on the exam room bed waiting for a check up. Beside the bed she has drawn a chair like those in the exam rooms. When she is in a room waiting for a check up, as she is in her drawing, Junie says that sometimes she feels scared and sometimes not so scared. Getting a back shot [a spinal tap or bone marrow aspiration] makes Junie feel scared. She feels not so scared when she does not get a back shot. Junie says that the people at the clinic are nice. Junie laughs and agrees that although she is alone in her clinic drawing that also means that there aren’t any doctors or nurses coming at her with needles. Junie smiles and agrees that for
her drawing she thought about what it looks like in the clinic without thinking about the needles and the not so good things that happen there.

While drawing the third drawing, Junie laughs when she realizes she has not left enough room for the second [nurse] figure in her drawing. She draws the figure anyway, allowing the nurse to overlap the television. Junie explains that she drew the nurse coming in with a needle while Junie is watching TV. Junie has drawn herself in the hospital bed wearing her own pajamas, not a hospital gown.

Junie thinks that needles are one of the worst things about having cancer. Needles hurt. Junie doesn’t like getting bruises from the needles either. The bruises remind her of getting the shot and sometimes hurt, too. She says that you get a finger poke most every day at the clinic. Getting a back shot [a spinal tap or bone marrow aspiration] makes Junie feel scared. Getting a back shot hurts a lot. When she gets a back shot they give her some sleepy medicine and she goes to sleep.

Junie thinks that having to stay at the hospital is one of the other worst things about having cancer. She does not like feeling sick and having to be in the hospital and away from home. Junie says that in the hospital she is lying down a lot. Junie is sometimes by herself in the hospital. Sometimes she has visitors, but not a lot. Junie’s family sometimes comes to see her in the hospital. Junie does not like staying in the room at the hospital. It’s boring. Junie disagrees with me, saying that she does not really feel isolated or lonely because her mom is always with her. She likes that her mom stays with her in the hospital. Junie adds that she likes the playroom at the hospital. She likes being able to make arts and crafts while she is in the hospital. When she is in the hospital, Junie’s family sometimes comes to see her.

Junie agrees that standing, sitting and lying down in her drawings reflects how she
has to start sitting or lying down when she is tired and doesn’t feel good. She agrees that when she is sick, things like shots happen to her instead of her going out and doing the things she wants to get up and do.

For her fourth drawing of what has helped her get through the tough times, Junie draws her mom. Junie drew her mother with arms outstretched to hug her then decided to add herself to the drawing. Now in her drawing, Junie and her mother are going to hug each other. Junie has drawn a heart on her mother’s shirt just like the heart she drew on her own shirt [in this and other drawings]. To help her get through the tough times, Junie’s mom holds her hand and sits beside her. Her mom makes Junie feel better. When she holds her mom’s hand Junie feels better. Her mom also stays with her in the hospital, which she likes. At this point in the interview, Junie’s mom comes in, gives Junie a kiss on the head and asks how everything is going. She tells Junie she will see her soon and leaves. Junie says that her dad also helps her by doing the same things as her mom [holding her hand, sitting beside her]. Junie agrees that having her mom and her family close to her and supporting her is a big part of what helps her.

For her final drawing, the drawing of her family, Junie draws herself, her mom and her dad calling their two dogs. In the drawing Junie and her family are going to go play with the dogs, which she likes. Junie’s family sometimes comes to see her in the hospital. Junie’s family likes to watch movies together. They go to the movies. Junie’s family goes bowling. Junie describes her dad by saying that he likes computers and music. Junie describes her mom by saying that she likes to visit J’s grandma who lives close by. Junie knows of the game I am reminded of by her fifth drawing in which you fall back into the arms of someone standing behind you, trusting that they will catch you.

Junie believes that having cancer has made her braver. It still makes her nervous
when she thinks about going [to the clinic or hospital], but she is more used to it now. She agreed that she is more brave about other things now, too.
In my first communications with eight year old Junie and her mother, they both came across as considerate and enthusiastic about their involvement in this project. In scheduling our interview, Junie’s mother said that after a day of receiving chemotherapy Junie usually felt sick and tired. They offered to meet me at the hospital on an “off” treatment day instead so that Junie would be feeling better for the interview. We agreed to meet the next week. When I met Junie, she was quiet, but smiled broadly as we were introduced. Though she had just come into the hospital from the warm weather outside, I noticed that Junie wore a sweater, identifying herself as a veteran, prepared for the chilly air-conditioned climate of the hospital. Her mother let me know that Junie was feeling a bit nauseous and had a sore mouth and throat from her chemotherapy treatments, but that otherwise her energy level was relatively good. Junie sat snugly on her mother’s lap hugging a favorite stuffed animal as I reviewed the consent and assent forms with her and her mother. She listened attentively and nodded as I explained the study. When I asked if she had any questions for me she shook her head then looked to her mother to see if there was anything she thought Junie should ask. As we prepared to begin the interview, Junie kissed her mom goodbye and settled in with me at a table in the playroom.

As we began the interview, Junie was rather quiet. When she did talk, she spoke from behind the sleeve of her sweater. This may have been a bashful habit, or a self-conscious attempt to hide any sores in her mouth from the chemotherapy. In these early interactions, Junie came across as quiet and shy, even a little anxious or unsure of herself. Perhaps because she was the youngest participant I had yet interviewed or because of her mother’s mentioning that she did not feel well, I found myself particularly concerned that
she be comfortable and at ease, telling her to be sure to let me know if she needed a break, a glass of water for her sore throat, or anything at all. Junie’s sweet demeanor along with her young age and tendency to look to adults for help may elicit particularly gentle behavior on the part of other adults she encounters in the hospital as well.

For her first drawing, the self portrait (Appendix B, Figure B1), Junie drew herself bright-eyed and smiling in a bright purple shirt. I asked Junie to tell me about her drawing, and she shrugged her shoulders, saying, “it’s just me.” When asked to describe herself, Junie did not focus on her physical condition, her cancer or treatment, but rather on the normal interests and activities that any young girl her age would enjoy. She told me that she likes animals and has three pets – two dogs and a fish. As I would learn during the interview, Junie feels well loved and cared for and in turn enjoys loving, caring for and playing with her pets. She also said that she likes to read chapter books and sing. Later, Junie smiled and agreed that she used as much space as she needed for her drawings, revealing a much more expansive style than I would have at first expected from her. Junie said that she is kind of shy when she first meets people. However, she smiled and agreed that her drawings are not small or shy just as she is not always quiet or shy.

Junie, eight years old at the time of our interview, said that she was six when she was first diagnosed with acute lymphoblastic leukemia (ALL). Junie explained that
leukemia is a cancer in the blood. Asked to describe herself before she had cancer, Junie focused on her physical appearance, saying that before she had cancer she had longer hair. Her hair was straight, but Junie does not know if it will be straight when it grows back. The changes Junie has undergone while she has been ill, including the physical changes such as losing her long hair, may continue as she moves toward recovery. She may literally look very different in the future than she did before her illness and treatment. In either case, there is no mistaking that Junie is a different person having lived with cancer. Before she had cancer, Junie explained that she did not have a lot of bruises from needles and IVs. These are again the physical signs of what Junie has endured. She described the bruises themselves as sometimes tender, but more than that, they are a visible reminder to Junie and potentially to others that she lives with cancer. During the interview Junie did not draw attention to her illness, instead choosing to emphasize her normal activities and interests. However, she recognizes that her hair loss and bruises do make her stand out as different – they identify her to others as a girl living with cancer.

For her second drawing of her in the clinic (Appendix B, Figure B2), Junie drew herself sitting on the exam room bed waiting for a check up. Beside the bed she drew a stool like those found in the exam rooms. When she is in a room waiting for a check up, as she is in this drawing, Junie said that sometimes she feels scared, but sometimes “not so scared.” Getting a back shot (a spinal tap or bone marrow aspiration), she explained, makes her feel scared. She said that she feels not so scared when she does not get a back shot. Junie laughed and agreed that although she is alone in her clinic drawing that also means that there is nobody coming at her with needles. For this drawing Junie thought about what it looks like in the clinic without thinking about the needles and things that happen there. In this drawing of the clinic there is a noticeable lack of anything
frightening – there are no needles, no medicine, and no doctors or nurses to administer them. Junie has distanced herself from the anxiety-provoking aspects of the clinic. She has drawn a great physical representation of the clinic (what the clinic “looks like”), including a wide range of color and detail, without including the negative events or feelings she has experienced there.

While drawing the third drawing of the “worst” thing about having cancer (Appendix B, Figure B3), Junie laughed when she realized she had not left enough room for the second figure in her drawing. She drew the figure, a nurse, anyway allowing her to overlap the television. Junie explained that she drew the nurse coming in with a needle while Junie is watching TV. In the drawing, Junie knows that the nurse, and needle, are coming, but she has distracted herself by watching tv. Junie drew herself, looking much the same as in her previous pictures, lying in the hospital bed wearing her own clothes – not a hospital gown. Junie does not appear to have lost her sense of self while in the hospital environment. She is not just another patient in an anonymous or exposed hospital gown. She could, in effect, be just any kid, perhaps visiting, the hospital. Better yet, she could get up and go at anytime since she is dressed and “ready” to go and get about her regular activities and life.

For Junie, the worst thing right now is not that the cancer makes her weak, or is potentially life-threatening, but rather the immediate physical pain of the needles used for blood draws, chemo treatment, and bone marrow aspirations. She is focused on the physical pain of her treatment. Junie thinks that needles are one of the worst things about having cancer. “Needles hurt,” she explained. Junie discussed the many ways in which she regularly has to cope with the pain of needles: Junie doesn’t like getting bruises from the needles. She explained that, even when not in the middle of treatment, “you get
a finger poke most every day” at the clinic. Getting a “back shot” (a spinal tap or bone marrow aspiration) makes Junie feel scared because it “hurts a lot.” When she gets a back shot they give her some “sleepy medicine” and she goes to sleep. Junie is relieved to know that she does not have to be awake during this procedure, however the anxiety she feels about the associated pain before and after the procedure, and likely over the need for this test and anticipated results, keep it at the top of her list of “worst” things about having cancer.

Junie also said that having to stay at the hospital is one of the worst things about having cancer. Although Junie seems to be generally positive, even when reflecting on living with cancer, she pulled no punches in describing the “worst” parts. Rather than choose only one thing, needles or being in the hospital, she included both and wanted to get across to me that both experiences are extremely difficult for her. She does not like feeling sick and having to be in the hospital. When she is in the hospital, she is removed from the safety and security of home. The hospital is an unfamiliar environment for Junie. It signals that she is sick and weak and must stay in bed to receive treatment and rest. Even towards the end of a hospital stay when she is feeling better, as a patient, she spends most of her time in bed. So whether she is feeling badly or better, Junie says that in the hospital she is “lying down a lot.” Junie does not like staying in the room at the
hospital. She explains that it is “boring.” This again points to Junie’s normally happy
and energetic personality. She does not like being kept “down” by feeling sick or by
having to stay in bed at the hospital.

Junie misses seeing friends and others she normally interacts with when not sick
and in the hospital. She explained that she has some other visitors, but not a lot. Junie
said that the people at the hospital clinic are nice. She knows that she can count on the
people in the clinic to be nice whether she has to have a “back shot” or just a routine
examination. Junie added that she likes the playroom at the hospital. She likes being able
to make arts and crafts while she is in the hospital. The playroom in a safe, needle-free,
environment in which Junie has the opportunity to get up and out of bed, interact with
other adults and children, and engage in a normal activity that she enjoys – creating art and
crafts.

Junie recognizes that she does not always have to be scared in the clinic and
hospital. As a result, she does not seem to generalize her fear or anxiety about these
painful procedures to all of her experiences at the hospital. She can relax, or at least be
“not so scared,” when she knows she is in for a more routine checkup or blood work. She
does not expend time, energy, or emotion worrying about a trip to the hospital unless she
has to (unless she knows she is going for a “back shot”). Otherwise, she can focus on
visiting a playroom, watching tv, or on the all the nice people who care for her at the
clinic. Being able to distinguish these events and her accompanying emotions, helps to
distance Junie from the negative thoughts, feelings and experiences until she has to face
them. Then she can face them and go back to her normal life. In this way, knowing what
to expect from visit to visit has helped Junie keep from dreading and anxiously fearing
everything associated with the hospital.
Junie’s self portrait and drawings of herself in the clinic and hospital showed a steady progression from standing, to sitting, to lying down. This progression is logical and realistic in Junie’s experience: patients have to sit on the examining table when they are in the clinic for a check up, and lie in bed when checked into the hospital. Junie agreed that standing, sitting and lying down in her drawings reflect how she has to start sitting or lying down when she is tired and doesn’t feel good. This posture of the patient also reflects a move from more active to more passive. Again, this is based in part on Junie’s waning physical strength, such that she feels the need to sit or lie and rest, as well as on her role as patient in which she waits to be operated on, treated and cared for by others. She agreed that when she is sick and has to lie down, things like shots happen to her instead of her going out and doing the things she wants to get up and do.

At first, Junie came across to me as a bit timid. Throughout the interview, however, she was able to ask for what she needed and to use the materials at her disposal to her best ability. Though she had frequently turned both to her mother and to me to ask for guidance, Junie was not afraid to disagree with me when she felt my interpretations fell short of or conflicted with her experience. After drawing herself as the only figure in the first three drawings, I asked if she felt lonely or isolated in the hospital. Junie said no, that her mother was always with her. Indeed, in her clinic picture, though she is alone, she has taken care to draw a stool which leaves a place in the room for another (her mother, a doctor or a nurse) to join her. In her drawing of the “worst” part of having cancer she turned the paper just the way she wanted it. This is indicative of Junie’s ability to manipulate the environment when necessary. Though she did ask if this move was ok, she did so only after she had already turned the paper and begun to envision just how she wanted the drawing to look. She checked in, it seems, for confirmation.
For her fourth drawing of what has helped her get through the tough times (Appendix B, Figure B4), Junie drew her mother with arms outstretched. Later, Junie decided to add herself to the drawing to show she and her mother about to hug one another. Junie drew a heart on her mother’s shirt just like the heart she drew on her own shirt in this and other drawings. To help her get through the tough times, Junie says that her mom holds her hand and sits beside her. When she holds her mom’s hand Junie said that she feels better. She also likes that her mom stays with her in the hospital. Junie’s mom cannot make the pain of the needles or her cancer “all better.” What does help Junie to feel better is holding her mom’s hand and knowing that she is there beside her – she does not have to face living with cancer, the needles or the hospital stays, alone.

Serendipitously, Junie’s mom came in at this point in the interview, gave Junie a kiss on the head and asked how everything was going. Junie nodded and said everything was fine. Her mom told Junie that she was waiting right outside and that she would see Junie soon. Junie smiled and waved goodbye as her mom left the room. We returned to the interview, and Junie continued by adding that her dad also helps her by doing the same kinds of things as her mom (i.e., holding her hand, being close). Junie agreed that having her mom and her family close to her and supporting her is a big part of what helps her. Junie knows that her mother and father love her and will be with her each step of the way.

For her final drawing, the drawing of her family (Appendix B, Figure B5), Junie drew herself, her mom and her dad calling their two dogs. In the drawing Junie and her family are going to go play with the dogs, an activity Junie said she enjoys. Just as Junie described normal everyday activities that she enjoys, she describes very ordinary things she enjoys with her family. Her focus here was on the normal everyday functioning of her family and the things they enjoy doing together. Junie’s says that her family likes...
watching movies at home, going to the movies, and going bowling together. Junie is also demonstrated that she is closely attuned to her parents, describing things that they enjoy, rather than just what they do with or for her. Junie described her dad by saying that he likes computers and music. Junie described her mom saying that she likes to visit Junie’s grandma. In her picture, she and her parents are all standing together and are all focused on a common goal: caring for and playing with their dogs, who Junie describes as part of her family. It is also a welcome thing for Junie and her family to be focused together on taking care of the dogs, not just on taking care of Junie and getting her through her illness and treatment. The dogs are something that need Junie’s care and attention. Finally, when I described a game I am reminded of by this drawing in which one person stands in front of another who catches them as they fall back into their arms. Junie was not immediately thinking of that game, but said she is familiar with it. In her drawing, each person in the family stands just in front of another member whose arms are outstretched to them. Junie trusts that her family will be there when she needs them. I was reminded of the image of Junie’s mother checking in to let Junie know she was there while Junie to smiled, waved good bye, and continued with the interview on her own. Being able to be dependent on her dependable and caring family, and on the medical staff at the hospital, has given Junie the confidence to go forward more independently as she grows stronger and older. She has been reassured by their support that she can do it.

Much of the action throughout Junie’s drawings involved potential action or passively waiting for something to happen (e.g., waiting for her checkup, a nurse is about to give her a shot, she and her mother are about to hug one another, the family is calling the dogs and about to take them out to play). This reflects Junie’s stance of watchful waiting to see what will happen next. She has been on her treatment for some time now.
She is nearing the point at which her doctors will reevaluate to determine if she is will need more aggressive treatment if her cancer is not responding as they would hope or if she is responding well (as it would appear), if she is ready to discontinue treatment. At this point, she is unsure what the future holds in store for her. When asked what, if anything, might be different about her in the future, Junie said she could not think of anything. Whatever the future holds, Junie believes that having cancer has made her “braver.” She said that she still feels nervous when she thinks about going to the clinic or hospital, but she is more used to it now. She agreed that she is more brave about other things now, too. Junie has earned this bravery by making it through each step of her illness, diagnosis and treatment. She has taken these experiences and emerged with a new meaning and perspective on the world: if she has made it through this far, she can bravely face whatever the future holds in store her. She has developed self-confidence and, with the loving support of her family, stands ready for whatever tomorrow may bring.
Appendix C

Steve

Figures D1a, detail and D1b, detail: Harry’s drawings of himself now and before cancer.
Steve: Interview

[Chose his pseudonym, Steve McNair, after the quarterback for the Tennessee Titans football team. Steve is a 10 year old caucasian male diagnosed with an Inflammatory Pseudotumor (IPT) of the chest.]

1. Kristy: It’s September 19. This is Kristy and I’m here with Steve [all names and identifying information have been changed to protect confidentiality]. Would you like to say hello?

2. Steve McNair: Hi.

3. [tape recorder turned off and rewound to let S. hear his voice]

4. K: Just to go over this again, I’m going to ask you some questions and have you do some drawings about what you think it’s like having cancer. You can ask any questions that you have any time you want, ok?

5. S: Ok.

6. K: Your mom is waiting outside if you need her and we can call T. [the child life specialist] if you want to talk to her. Any time if you decide that you want to stop and take a break or just stop we can do that, ok?

7. S: Ok.

8. K: I want you to tell me about your experiences so that I can learn about what it has been like for you to have cancer. You’re the expert, so there are no wrong answers. You can do the drawings any way that you like.


10. K: Ok. On this first page I just want to get some information about you. So, “I am... years old.”

11. S: [writing “10”]

12. K: And here how long it has been since you were diagnosed, or how old you were when you were diagnosed.

13. S: How long?

15. S: Huh... I don’t have any problem with doing this [pointing to age question], but on the kind of cancer I have [pointing to next question]... it’s very long and I do not know how to spell it.

16. K: Ok. Do you know what it’s called?

17. S: It’s called an inflammatory pseudotumor.

18. K: Ok. I can probably help you with that.

19. S: Now how long... I found out I had cancer when I was eight. I had a collapsed lung, ok? That started it. There were many doctors. Well... I wouldn’t say thousands, but we went to more than one. That should be... one should have done the job. I kept riding my bike. I was really active, but after I got done doing something really athletic, running, stuff like that, I would start wheezing, coughing really bad. Kids wouldn’t be as tired as I would. In my head I was like, “what is going on here. I mean, this isn’t right.”

20. K: Wow. That must have been scary.

21. S: Yea. Soon after we went to doctors. This one doctor, he was my doctor for a very very long time. He told me I had asthma. It was always asthma. I had about five inhalers. I would take all these inhalers, different kinds. We kept going. Asthma, asthma, asthma. They never listened to my lungs. They never ordered a chest x-ray or anything like that. The problems kept getting worse, you could say. The reason why it kept getting worse is because it kept growing.

22. K: Your tumor kept growing?

23. S: Yes. This thing was the size... no bigger than this [holds fingers up about the size of a quarter], but now it grew to the size of a grapefruit. It wrapped around the aorta. And it wrapped around blood veins that are real important to the heart, that feed the heart. It’s wrapped around all of that stuff, and to do do surgery is really risky. I mean, what they’re saying is that even to try I wouldn’t live through it.

S: Yea. So that’s why they’re not going to do that. After that doctor my mom kept seeing that I kept getting worse and worse and worse... each day practically. After it got to a certain point she was just fed up with it. She was like, “I’m taking you to more doctors, and they are going to tell us something we don’t know.” So we went to a second doctor and he said it was asthma, too. Then we went to another doctor. Same old same old, “asthma.” Then we moved to a different city where there were thousands of doctors – and I’m not lying about the thousands. It’s a big place. We went in and he did what no other doctor did: he listened to me, listened to that one side of my lung, and said “I hear no lung capacity in this left lung, so I’m going to order him a chest x-ray.” I was really young yet. I didn’t know anything about collapsed lungs or any of that. I went for a chest x-ray, and I was like “what? What’s that?” My brother sat me down in his lap and said “don’t be scared.” And I was like, “look at you!” We got transferred to Children’s and that’s where they ordered me a CT scan. That’s when they found out that I don’t just have a collapsed lung, I have something they don’t know what it is. We know now that it was a tumor. Then it got hard. They brought in this tube and they said we’re going to stick this up your nose. I was squeezing onto the bed rails. I didn’t want to do it. They made my nose bleed and they couldn’t do it. They said they would come try again later. I was like, “whew!” but I had to worry about later. I was so nervous. They came back to do it again. I was struggling saying, “I’m not going to do it!” They had four nurses holding me down because I was literally not going to do this. I don’t know what they did to make me do it, but I know that they were holding me down. My mom had to leave the room because it was hurting her. They finally got it in and finally they took it out. My mom came back in and gave me hugs. I was sick... tired... and shaky. I didn’t want to do that. It was just scary. And for my mom, too, I guess. I was not knowing what was happening. Then everybody told me what was going on – that I had a tumor. They didn’t know what kind, but they knew it was very rare. I’m either the first case or the second case in either the whole world or in Texas. It’s not that it’s rare, it’s just where it is. Then they decided that they wanted to do a biopsy. I didn’t know what a biopsy was. I didn’t know that it hurts! They opened me up and found that they couldn’t do anything because of what it was. They started me on steroids. That was shrinking it. Then it didn’t anymore. Then they started me on something else. It was also gross. That didn’t do one thing. As a matter of fact it grew while I was on that. That’s when they started me on chemo. I’ve been on chemo ever since then. Chemo shrunk it until it couldn’t do it anymore. So, I was off of chemo for four or five months. After all that, some of it grew except outside the lung and now my lung is collapsed again. That’s where we are now.

K: You’ve been through a lot. Thank you for giving me the background.
27. S: Yea. It’s a long story.

28. K: Well, it’s good for me to know. And I’d like to talk more about it as we go along, if that’s ok.

29. S: Sure.

K: Are you ready to do these drawings? Do you need anything before you start?

S: I’m ready.

K: Ok. I’m going to have you do five pictures all together. You can draw them any way you want and use any colors that you want. For the first drawing you can draw a picture of yourself.

S: Myself?

34. K: Yes.

35. S: Ok, I don’t draw very good people, but I don’t draw stick men.

36. K: That’s just fine.

37. S: Is it ok if I outline it first and then fill in the colors?

38. K: That’s fine.

39. S: Ok. [drawing #1... 5 minutes total] Ok.

40. K: That’s a great hat.

41. S: Thanks! I figured out how to draw hats just by trying. [looking at his picture] It turned out pretty good.

42. K: So tell me a little about your drawing.
43. S: Well... I guess I drew me when I was active. You can’t really tell because I’m just kind of sitting there.

44. K: Ok. So this is you when you were more active?

45. S: Yea.

46. K: Do you think it describes you pretty well?

47. S: Well, it depends. I can draw lots of things. I can draw me running, jumping...

48. K: Can you think of other things that describe who you are?

49. S: If I drew a picture of me running or jumping that would describe me as active.

50. K: What about if you were describing yourself to someone who didn’t really know you too well?

51. S: I would describe me as... let me think... I’m nice. I can describe that. If anyone asked me to do something I’d do it.

52. K: You like to do things for people, or to help out?

53. S: Yea. So... [pause]

54. K: Anything else you can think of that describes you?

55. S: Not really.

56. K: What about anything that doesn’t describe you? Like, “I am not shy.”

57. S: I cannot say that I am not shy – because I am. [laughing]

58. K: [laughing]

59. S: When it comes to something I really want to do I’m shy at the moment, but then I can’t back out of it and I’ll do it. Like riding really big rides. I rode every ride at Six Flags. I was scared, but... I had to have someone I really trusted tell me it was not too scary. I wouldn’t do it at first, but then I found the courage to do it. On some occasions it’s not very much different from being in hospitals and having to
get stuff done to you, except that on rides you know that you can back out before you’re there. Here you can’t do that.

60. K: That’s a great description. Being in the hospital is like going on a rollercoaster ride. You have to build up the courage to do it. Like riding the rides do you sometimes find that it wasn’t as scary as you thought it would be.

61. S: Sometimes. Sometimes it’s worse, but you have to do it. You can’t back out.

62. K: You just need courage to get through it?

63. S: Definitely.

64. K: Ok. Can you think of any ways that you’ve changed since you’ve had cancer?

65. S: Yea. I think I’ve changed. Can it be physical? It doesn’t have to be personality?

66. K: It can be anything.

67. S: I think I’m not as active as I was because of how sick I’ve gotten.

68. K: Has that been hard on you? It sounds like you were really active.

69. S: Yes. It has. I was really active. I used to ride bikes all around the neighborhood with my friends and I can’t do that anymore. I can ride a little, but not like we used to.

70. K: Do your friends ride the shorter distances with you now?

71. S: Well, we haven’t been riding our bikes as much, but we rollerblade some. They can keep up better. They can go faster and they won’t get as tired as I will. they’re just a lot better at sports.

72. K: Ok. Anything else that you can think of that has changed for you since you’ve had cancer?

73. S: Um... I’ve met new people. I went to Camp Esperanza. All my friends up here [at the hospital] and all the nurses. There is this one nurse who is like my best friend and I would never have met her if I hadn’t had cancer.

74. K: So now you have new friends, the other kids from camp and the nurses?
75. S: Yea. They’re the best.

76. K: Ok. Anything else?

77. S: I became an ambassador. That would never have happened if I wouldn’t have got cancer.

78. K: What do you do as an ambassador?

79. S: I get to go to baseball games, golf tournaments... and I talk about having cancer and other kids who have cancer so that other people know about it.

80. K: That’s great.

81. S: Yea.

82. K: Anything else?

83. S: [pause] Not really.

84. K: Ok. What about in the future?

85. S: In the future? Yea. I’ll be playing sports again. I’ll be playing the same things my dad has played. My mom isn’t married to my dad anymore, but... My dad has played basketball, football. I’ve played basketball, soccer and I’ll be playing football next year.

86. K: So in the future you’ll be back to playing all those sports?

87. S: Well, in the future I know it will be a lot harder on me to play sports and stuff like that. But that’s what I hope I’ll be doing...

88. K: That’s what you hope for the future?

89. S: Yes.

90. K: Anything else?

91. S: Um... I want to be a volunteer at the hospital and help kids out.
92. K: Ok.

93. S: I can understand what they’ve been through because it happened to me.

94. K: Right. You want to help other kids going through what you’ve been through?
95. S: Yes.

96. K: Ok. For drawing number two I need you to draw a picture of yourself in the hospital or clinic.

97. S: In the hospital or the clinic?

98. K: Yes.

99. S: Ok. Can it be in front of the hospital? Can you be outside or does it have to be inside?

100. K: Let’s say “in” the hospital.

101. S: In? Ok. [drawing #2... 10 minutes total] Almighty, I’m done.

102. K: Did you want to use any of the other colors at all?


104. K: Is that smoke coming from the plane’s engine?

105. S: Yea. I added that. [smiling]

106. K: Ok, then. [smiling] Can you tell me about your drawing?

107. S: Well, I like looking at the trains and the airplane. That’s me [pointing]. I usually go through there with the front desk and everything.

108. K: What do you like about the trains?

109. S: Well... It really looks like Dallas. It’s fun to watch them go around and around and up high.

110. K: So in this drawing you’re watching the trains?
111. S: Yea. [pause]

112. K: Can you tell me about the hospital? About what it’s like for you?

113. S: Um... [pause]
114. K: Can you think of how you feel when you’re in the hospital? What you like or what you don’t like?

115. S: Yea. I don’t like getting chemo. I know that it helps me, but I don’t like it because I know it makes you sick.
116. K: Ok. You don’t like getting chemo because you know it makes you sick.

117. S: Yes.

118. K: Ok. Anything else?

119. S: Everybody here... they’re all my friends. I have one friend who’s not here today. His name is Sean. He’s really nice. I like everyone.

120. K: How do you feel when you’re in the hospital or the clinic?

121. S: How do I feel? Well, I used to be happy. Not happy that I have a tumor or anything, but... when they took me off chemo I was happy because I knew I didn’t have to have it anymore. But now I’m back on it I get nervous. I’m glad because I’m going to get to see everybody.

122. K: You get nervous about coming to get chemo?

123. S: Yea. I know it makes you sick. And tired.

124. K: But you like seeing your friends?

125. S: Yes.

126. K: In your drawing are you coming in or going out?

127. S: I don’t know [laughs]. I guess it could be night [adding stars & moon] and we’re on our way out. I don’t know how to draw stars too well.

128. K: That’s ok. I understand what those are.
129. S: Then we have to have some moonlight [adding yellow streaks of moonlight].

130. K: Is it often night when you leave?

131. S: Sometimes. We’ve left at two o’clock in the morning.
132. K: All right.

133. S: This is the parking lot and the driveway and the parking guy or security guy who’s always there talking to everybody.
134. K: Ok. Now I need you to draw what you think is the worst thing about having cancer.

135. S: Hmm... I guess the worst thing is... I don’t really know what it looks like, but I’ll try to draw a tumor. I think the worst thing about cancer is my tumor. I’ll just make a big round shape the size of a grapefruit. [drawing #3] Now I’ll draw... [drawing] I’m going to make that the thing, the vein, it’s wrapped around. Do you know what an aorta looks like? I know it’s something your body can’t live without. It’s a big part of the heart. I’ll just make big circles, I guess, with a whole bunch of veins. I’ll make it red. All right. I don’t really know what a real heart looks like, but... [drawing... 6 minutes total]

136. K: That’s all right.

137. S: So, I think I’m done.

138. K: Ok. Tell me about this. What makes the tumor the worst part about having cancer?

139. S: Well... It’s the main thing that they’re trying to get rid of and they’re saying. The worst thing is... where it is is bad... It’s [pointing to heart in drawing] getting squished.

140. K: It reminds me in your drawing of the way you were describing it earlier. You said that the tumor is wrapped around all these veins that are important to the heart, that you need to keep your body going.

141. S: That’s also why it’s the worst. If they tried to cut it... it’s too close to the heart so [flapping arms and hands like wings] I’d be floating away [looks up to the ceiling / sky]. And if they don’t cut it and it keeps growing...[again flaps arms like angel’s wings and looks up to the ceiling].
142. K: That is the worst. It’s not good to have surgery and it’s not good to leave it alone.

143. S: Yea.

144. K: How do you feel when you look at this drawing?

145. S: I just tried to draw what I know is going on.

146. K: That must be very frustrating when you think about how long it took to get diagnosed.

147. S: Yes. It’s very frustrating when I think about it because... Sometimes I wish that... See, if they just would have started chemo when it first was beginning, I would never have had to go through with this. It would have gone... shrunk away. But now since we waited too long it just didn’t do that. So... That’s what makes me frustrated and really upset.


149. S: Yea.

150. K: All right. Are you ready for the next drawing?

151. S: Yea.

152. K: Ok. For this one I want you to draw what helps you get through the tough times.

153. S: All right. [drawing #4] This might take a while.


155. S: [While S. is drawing, his mom comes into the room and waves to him.] Hi.

156. Mom: Are you doing ok?


158. K: We have just one more drawing to go.
159. Mom: Ok. I’m just out here when you’re done.

160. S: Ok. [waves to mom then continues drawing] Now I’ll start coloring. [Fills in drawing with colored crayons... 11 minutes total] Ok.

161. K: Ok. Can you tell me about your drawing?

162. S: It’s my family and friends. They help me get through everything. Especially my mom.

163. K: Is she this one with blonde hair?

164. S: Yea. This is my mom. This is my aunt, my cousin Marie, my cousin Teresa – she’s older than me. She’s twelve. Marie is eighteen. This is my friend Josh. He’s the same age as me. We’ve know each other for three years. He’s a pretty nice guy. From the time that we moved, before I was finished unpacking he’s known me. This is my uncle Dave. That’s my dog. This is my cat. I have more friends, too.

165. K: How have this group of people helped you the most?

166. S: They really care, you know. They talk to me about it. They tell me everything is going to be ok. They’re always beside me. That’s mainly what I need.

167. K: When you were first drawing this one I thought you were drawing angels. I thought these arms were their wings [pointing].

168. S: They definitely are angels. That’s just how I draw arms, but they are angels. These are the fingers and I draw the thumbs separate [pointing]. They are my angels.

169. K: Ok. For our last picture I need to draw you and your family with everyone doing something.

170. S: Ok. Do I have to draw them all again, because that was kind of hard.

171. K: You can just draw your immediate family if you want.

172. S: Ok. [drawing #5... 5 minutes total] Ok, I’m done. I drew us at the theater. I’ve never tried to draw this stuff before, so I’m very proud of myself.
173. K: Yea. That’s great. Is that you and your mom?

174. S: Yea. I forgot to color her hair. [drawing]

175. K: Ok. Tell me about the theater. Do you like to go to the theater.
176. S: Yea. We go see a lot of movies together.

177. K: You like doing that together?

178. S: Yea.

179. K: Tell me a little about your mom.

180. S: Well, she’s nice. She’s very silly. She likes to play around a lot. She’s very very sensitive. Things that would usually make people cry make her sad. Very nice things will make her sad. Not sad, but you know, “that’s very nice of them to do that.”

181. K: What else do the two of you like to do together?

182. S: Everything. We see movies together. We bike ride together. We walk together. There’s stuff that we just do together. We watch all kinds of movies together. I like snuggling with my mom. Getting under the covers and snuggling. It’s comfy and it’s comforting having her beside me.

183. K: Ok. I think we’re just about done. If you had a love who was diagnosed with cancer what advice would you give them?

184. S: Oh, man... [pause] Something I would say is be prepared for anything. I don’t really know what else. I have to think about it.

185. K: Ok. I want to look over these pictures together. I’ll tell you some of the things that I noticed about your pictures and you can tell me if what I say sounds right or not. Ok?

186. C: Ok.

187. K: Ok. In doing this research I’ve noticed that sometimes kids will draw themselves really big on the page and sometimes, like you did here [drawing #1], they draw themselves really small.
188. S: Yea. It’s pretty small. I know its’ supposed to mean something, but I just honestly sometimes draw myself small and sometimes draw myself big. This one’s just small.

189. K: This one’s just small?
190. S: Yea.

191. K: Ok. [pause] Do you notice anything that’s different about you or about how you are feeling when you draw yourself big versus when you draw yourself small?

192. S: Hmm... I don’t think so.

193. K: Ok. What about today? How are you feeling today? You’re in the clinic for your treatments. How are you feeling?

194. S: Pretty good. I don’t like the chemo. It makes me sick. But I’m not sick right now.

195. K: Ok. [pause] Are you thinking about when you will be sick.


197. K: Ok. [pause] This next picture [drawing #2] looks kind of fun. Here’s you watching the trains and the plane. You’re smiling and saying “wow.” You told me that this would be you on your way out of the hospital, so whatever you had come in for was over. So it all looks pretty good. But then... [pointing]

198. S: [laughs] Yea. The plane’s on fire.

199. K: The plane is on fire. That made me think of your story of how you were diagnosed. You were going along, being active, being a kid, having a good time, and without you knowing – or all those doctors- that tumor was growing.


201. K: So it was like this sort of happy scene that has this danger looming. Does that sort of fit for you?


204. S: Yea.

205. K: Yea. [pause] Ok. This one I already mentioned that these reminded me --

206. S: My angels.

207. K: That’s right. I like this last one [drawing #5] with you and your mom at the movies.

208. S: Yea.

209. K: You guys like to go to the movies to kind of get away from it all?


211. K: The other thing I noticed was that the two of you have this big theater to yourselves.

212. S: Yea.

213. K: All these empty seats with nobody in them – the theater all to yourselves made me think of you and your mom sticking together and sort of taking on the world. Sticking together to see each other through this.


215. K: Yea?

216. S: Yea.

217. K: Ok. I think that is all that I have for you. Do you have any questions for me?

218. S: No.

219. K: No questions?

220. S: No.

221. K: Ok, then. Thank you for sharing your story with me.
222. S: No problem. It was nice to meet you. Good luck on this... and with the baby.


224. S: Do you know what you’re having?


226. S: That’s cool. Good luck.