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School Response to Families with Children with Cancer

by

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## Abstract

In this qualitative study, in-depth interviews were conducted with 17 sets of parents who have children with cancer. Measures were used to assess how schools may or may not have supported these families during this time.

For the case studies, data were collected using parent demographic surveys, parent interviews, child interviews, and principal and educator surveys. Likert scales were included in surveys given to parents and teachers. When appropriate, information from one data source was used to substantiate and expand upon information provided by another.

In this study, the research data was examined using two complementing models, Bronfenbrenner's (Bronfenbrenner, 1994) bioecological model and McCubbin and Patterson's (1983) Double ABCX model. Both models examine the effects of "over an extended period of time" (Bronfenbrenner, 2001). The bioecological model emphasizes family interactions amongst themselves and other systems, including schools. It examines the interplay between three systems, the family, hospital, and school and how these interactions affect the family and the child with cancer.

McCubbin and Patterson's (1983) Double ABCX model of families examines the impact of the original stressor on a family according to a pile up of stressors, the family's perception of resources, and their management of these resources and stressors. The philosophy of moral pedagogy, where the virtues relative to the process of teaching are congruent with the personal values of the teacher, further serves to assess the relationship between the school and the family (Sockett, 1993). Noddings' (1992) ethic of care is taken into consideration when examining the school-parent relationship in terms of moral pedagogy. Noddings defines caring as a connection or encounter between two human beings. Within the school setting, the student and his/her family have had experiences which may or may not include moral pedagogy. The major goal of this study was to assess whether schools are a stressor or resource for families using the Double ABCX and the bioecological models. Results generated ideas about how the educational system can work more effectively with families.

## **Dedication**

This is dedicated to Jason, Shana and Rachel,  
and  
to the  
Courageous Families Willing to Share Their Stories

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## Chapter 1

### Introduction

The experiences of parents of children with cancer and their interactions with school personnel have received very little attention in the research literature. This study focused on the experiences of 17 families with adolescent children currently being treated for cancer or within 5 years of treatment. The main goal of this study was to determine whether two complementary, theoretical models, McCubbin and Patterson's (1982) Double ABCX model and Bronfenbrenner's bioecological model (Bronfenbrenner & Ceci, 1994), can help explain the experiences of parents and schools over time when confronted with a child's cancer. Within these theories, the paper asked whether schools are a stressor or a resource for families with children with cancer.

This study also investigated the support the school system provided to the parents in terms of moral pedagogy (Sockett, 1993; Sockett & LePage, 2002), specifically in terms of caring (Noddings, 1992; Gilligan, 1982). Is there interplay between support for families and moral pedagogy? Did the schools' supportive efforts reflect parents' needs?

Today, the cure rate for pediatric cancer is 65% (Candlelighters, 2003). Because the number of children surviving cancer is growing, more children are able to return to school. The survivors are considered to have a chronic illness because the treatment can result in a residue of side effects (Thompson & Gustafson, 1999). Cancer is not only a chronic health condition, it is considered to be a high incidence condition (Clay, 2004). Cancer is the third highest chronic illness after asthma and cardiac conditions in children (Kaffenberger, 2006). It occurs in one in 660 children.

Adapting to and coping with childhood cancer takes a toll on each family member and on the family system with sequelae that can take years to develop (Keene, Hobbie, & Ruccione, 2000; Kupst, 1994; Kazak, 1989). Thus, in this study, I asked what it is that parents of children with cancer need from the school system. What are the stressors on parents? How are parental needs supported by the school microsystem? Furthermore, I examined the interplay between the family system, the school system, and moral pedagogy.

### Objectives

In this study, in-depth interviews were conducted with 22 parents who have had a child with cancer (17 families). Qualitative measures were used to explore how these parents coped with having a child with cancer. The main question of this study is as follows: Are schools more often a source of stress or a positive resource for families with children with cancer?

Other objectives for this research are to:

- 1) Describe and compare the impact of cancer on the parents.
- 2) Describe if and how schools support parents in terms of moral pedagogy.
- 3) Compare and contrast how parents of children with cancer are treated by schools.
- 4) Explore whether ethnicity, gender, family constellation, and socioeconomic status can result in differences in how schools treat parents of children with cancer.
- 5) Discover what factors determine parental advocacy for services for their children with cancer.

- 6) Make recommendations, if indicated, for changes in educational policy regarding the needs of families who have children with cancer.

## Chapter 2 Literature Review

### Introduction

Research in the area of childhood cancer has focused on children with cancer or their parents. Childhood cancer literature has focused on physical health, psychological, and academic issues. Parental issues in relation to their child's cancer have focused on how they have coped in general. However, there is a dearth of literature on both the parents' needs and the child's concerns when he or she returns to school.

### Family Systems

To better understand what the diagnosis of cancer can do to the family dynamic and functioning, it is helpful to first consider a model of a typically developing child. A child is part of a family, which is a social system (Garbarino & Abramowitz, 1992). All systems, whether cellular at the organic level, or social between members of a system or systems, seek equilibrium as conditions change internally or externally (Garbarino & Abramowitz, 1992; Michel & Moore, 1995). In human development, both Bronfenbrenner's (2001) bioecological model and Sameroff and Chandler's (1976) transactional model emphasize that development is bi-directional and continuous. Using Bronfenbrenner's (1994) bioecological model, a child and his family are at the center in their microsystem, encircled by the exosystems of the parent's work place or the community center, which is then encircled by the macrosystem (See Figure 1). The mesosystem represents the interactions among the family, the school, and the community.

In the bioecological model, Bronfenbrenner (1992) takes into account the child's biological heritage such as his genetic makeup and specific biological traits. This model also includes the chronosystem, which takes into account the dimension of time. The family influences the individual members' expressions of illness and health through the processes of socialization and the transmission of basic values, beliefs, attitudes, hopes, and aspirations (Shepard & Mahon, 2002). Each family is its own unique configuration defined by individual, ethnic, and cultural influences.

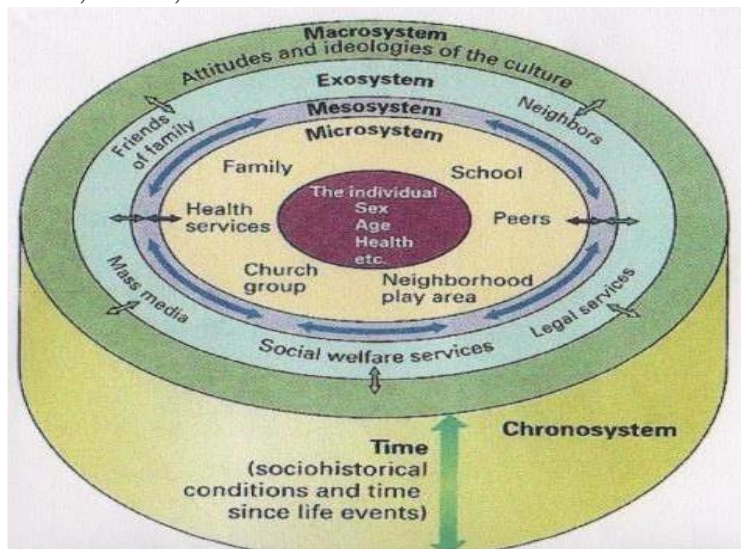


Figure 1: Bronfenbrenner's bioecological model. Santrok, J.W. (2007)

[www.aifs.gov.au/.../keyresearchquestions.html](http://www.aifs.gov.au/.../keyresearchquestions.html)

When a child is diagnosed with cancer, his/her body's equilibrium is disturbed at the cellular level. The family system is equally shaken because "developmental phenomena can exist simultaneously at different levels (e.g. cells, tissue, organ system, individual, family)" (Michel & Moore, 1995, p.22). Quite often, the primary caregiver, usually the mother, and the child with cancer, form a dyad. In a two-parent family, the father is usually working, and additionally, takes on more responsibility for the other children. The mother usually deals with all the medical issues, which seem endless, and primary emotional support for the child with cancer. Most research focuses on the mother-child dyad including how a mother's coping skills impact the child with cancer. The family is faced with a life-threatening illness, and goes into crisis mode (Shepard & Mahon, 2002). At the time of diagnosis, the primary concern is the survival of the stricken child. A support network is often pulled together by friends and family. Figure 2 below represents this imbalance in the family system when a child is diagnosed with cancer.

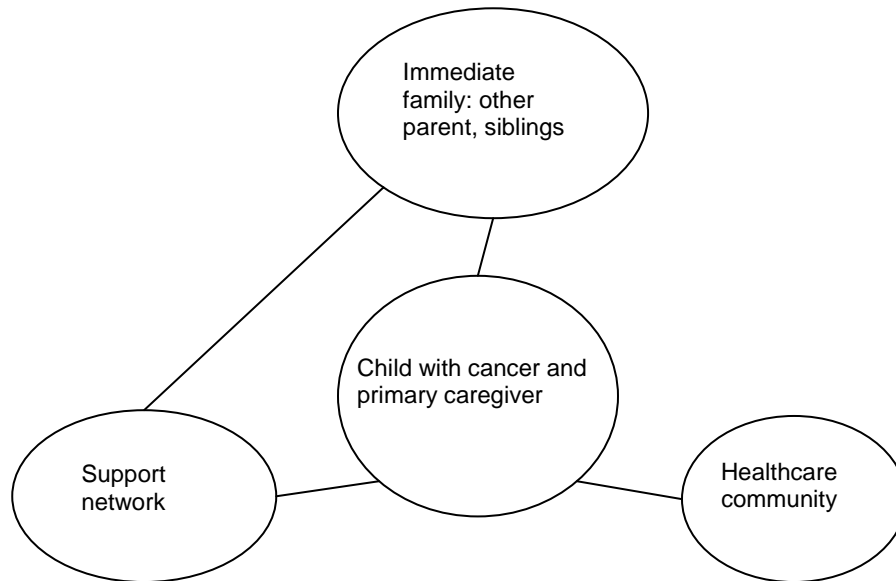


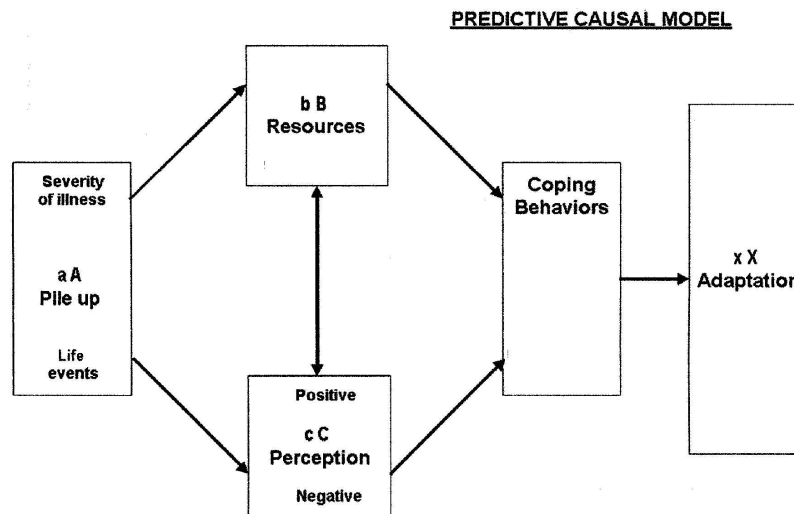
Figure 2. This off-balance model aligns the primary caregiver with the child with cancer.

The literature supports the bioecological model and the family systems model in relation to examining a family dealing with childhood cancer (Carpenter & Levant, 1994; Kazak, 1994; Kupst, 1994; Power, DuPaul, Shapiro, & Kazak, 2003). The family must interact with the hospital, agencies, and social support networks. Issues related to disease and treatment involves siblings, parental employment, and medical/nursing staff interactions (Kupst, 1994). This multidirectional and dynamic orientation emphasizes a developmental, non-pathological perspective that includes the developmental level of the family.

Along with Bronfenbrenner's (1994) bioecological model, another applicable model to provide a framework for looking at school response towards families with children with cancer is the Double ABCX Model by McCubbin and Patterson (1983). This framework is a reworking of Hill's (1949) ABCX family crisis model. In Hill's

model, A, the stressor event, interacts with B, the family's resources to meet the crisis and with C, the definition or family perception of the event, to produce the crisis, . In brief, this model identifies, describes, and integrates the process components of family behavior in response to a stressor and to a family crisis over time. The process of a family reacting to a stressful event is seen as a part of ongoing family life. The family's reaction can be either positive with growth within the system or negative, falling into dysfunction. A family either adapts or does not adapt to this stressor. This theory has been applied to family reactions to stress throughout the literature of special education (Hanson and Lynch, 2004; Xu, 2007). This model is used for studying individual and family efforts in coping with stressful events over time while dealing with the accumulating demands and additional crises.

McCubbin and Patterson (1983) have adapted Hill's (1949) original model as a foundation to add post-crisis variables in order to describe their work with families of children with disabilities and chronic illness (Hanson and Lynch, 2004). In other words, this model considers a pile-up of stressors and strains, aA, while bB denotes the family's adaptive resources (McCubbin & Patterson, 1983). Factor cC considers the family's perception of the original stressor event, as well as to the added stressors and strains, including what can be done to bring the family back into balance. Family adaptation balancing (xX Factor) has three main elements: 1) the individual family member; 2) the family system, and 3) the community of which family members and the family unit are a part. This theory has been applied to family reactions to stress throughout the literature of special education (Singer & Irwin, 1989; Hanson & Lynch, 2004; Xu, 2007). In this study, I ask whether families with children with cancer initially see schools as a stressor or a resource and if this perception changes over time.



Adapted from: Katz, 2002, p.264

## **Coping and Adapting to Cancer as a Chronic Illness**

Disability is the one minority that anyone can join at any time, as a result of a sudden automobile accident, a fall down a flight of stairs, cancer, or disease (Shapiro in Miller & Sammons, 1999, p.29).

The current definition of disability refers to reduced function or loss of a particular body part or organ (Heward, 1996). Disability can also be defined as a long-term reduction in ability to conduct social role activities, such as school or play, because of a chronic condition (Newacheck & Halfon, 1998). Cancer is referred to as a chronic illness. The term, chronic illness, refers to conditions that affect one or more body organs, representing an active disease process that may last many months or a lifetime (Lehr, 1996). A chronic condition in a child affects all members of the family system as well as the child himself (Kazak, 1989).

Cancer as a chronic condition brings stressors to the family system. These stressors require adaptation and coping. Adaptation is a broad, hierarchical concept describing a person's accommodation to or compliance with environmental demands, such as school, work, marriage, peers, or having a serious illness (Kupst, 1994). It is a dynamic process, as one is never fully adapted to an ever-changing environment. Coping is under the umbrella of adaptation, with researchers commonly citing the formulation by Lazarus (1991), who defines coping as cognitive and behavioral efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person (p.112) (Engel & Melamed, 2002; Kupst, 1994).

Because family systems theory is based on an adaptation of general systems theory that sees systems and subsystems as being composed of interrelated and mutually reciprocal parts that maintain a dynamic state of balance or homeostasis, a change in one part is related to changes in other parts (Michel & Moore, 1995). Therefore, a childhood illness such as cancer, according to family systems theory, requires attention to interrelationships among additional sets of variables, along with those traditionally identified in studies of stress and coping (Bearison 1998). These variables will be examined in the research and include the following: psychological distress of each family member, parent relationships and responsibilities, the family's support system, and the family's ongoing relationship with medical and educational systems. Post-traumatic stress will also be discussed in relation to issues of stress and coping with childhood cancer.

Another stress in dealing with childhood cancer is having the threat of loss continually hanging over each family member's head. This has been described by Koocher and O'Malley (1981) as the Damocles syndrome, so named for the legendary Damocles, who, while being honored at a banquet, looked up and saw a sword suspended above his head by a horsehair. This is how a childhood survivor of cancer feels—happy to be alive, but frightened that a new tumor or reoccurrence is in the future. Parents often feel the same sense of dread.

Rolland (1990) has labeled this threat of loss as anticipatory loss. He fits this theory of anticipatory loss into a family systems-illness model that integrates psychosocial types and phases of illness with family variables. His thesis is that the anticipation of loss in physical illness can be as challenging and painful for families as the death of a family member. Families face an enormous challenge anticipating possible



future loss, and their experience with this protracted, threatened loss evolves with illness, along with individual and family development. Rolland understands the enormous challenges to families over the course of life-threatening illness. As such, families must live with constant uncertainty. Yet, at the same time, families must work simultaneously to sustain hope and cope with degrees of uncertainty.

Along with the fear of anticipatory loss, parents of children with cancer have concerns even if their children survive. A “cured” child often experiences what is called late effects, which are complications, disabilities, or adverse outcomes that are the result of the disease process, the treatment, or both (Hewitt, Weiner, & Simone, 2003). Late effects may be easily identifiable (e.g., amputation) or direct effects on function (e.g., severe cognitive impairment). Other late effects can be subtle and noticeable only to the trained eye (e.g., scoliosis) or only identified via screening (hypothyroidism, infertility). As many as two-thirds of survivors experience late effects from chemotherapy or radiation that develops beyond five years from diagnosis (Hewitt, Weiner, & Simone, 2003). These late effects can include, but are not limited to, cognitive impairment, fertility problems, alterations in growth and development, organ system damage, chronic hepatitis, and second malignant growths (Hewitt, Weiner, & Simone, 2003; Keene, Hobbie, & Ruccione, 2000).

### **Parents of Children with Cancer**

McQuown (1980) subtitles her chapter on parents of the child with cancer using the phrase “A view from those who suffer most.” McQuown (1981) describes leading a panel of parents who discussed the challenges of having a child with cancer.. Most parents are shocked at the time of diagnosis (Adams & Deveau, 1993). Sometimes parents and children are told at the same time and sometimes the parents are told beforehand. Many parents initially think their child is receiving a death sentence before adjusting to the uncertainty of the time ahead. They search for an explanation and feel sorrow, anger, and a loss of control. When this crisis phase is over, parents prepare for the long-haul phase (Rolland, 1990).

It is in the long-haul phase that parents are ready to gather information from the experts and learn (Goodnow, 1995). To gain some measure of control over the situation, parents, especially mothers try to be active in the treatment process by helping with medication compliance (Bearison, 1998). The mothers are developing a sense of self-efficacy to help them cope (Bandura, 1989). The parents on the panel said they could never use denial as a means of coping because they lived with the diagnosis every day (McQuown, 1981). One parent said “...you don’t necessarily dwell on it. I find it difficult to believe that anyone can totally deny that their child has a catastrophic illness (p.198).”

The strains of childhood chronic illness on the family are unlimited, especially on the parents. Among the lists of stressors parents with which must cope are juggling the demands of the illness and medical treatment, facing uncertainties about the future well-being and mortality of the child, Rolland’s (1980) anticipatory loss, as well as dealing with emotional, and academic limitations of the child (Barakat & Kazak, 1999). Parents also must deal with financial strains, changes in roles and routines, communication breakdowns with family and friends, and lack of leisure time. An issue in a young family is whether to have more children (McQuown, 1981; Adams & Deveau, 1993). Additional factors unrelated to the illness may tax existing parental coping mechanisms. These include prior deaths, low socioeconomic status, and low levels of social support.

The panel in the McQuown (1981) chapter talks about the stress that cancer places on the marital relationship. One couple says the illness of their child made them closer and changed their priorities forever. Another couple feels that it can bring the family closer, but that there are problems also. The working father feels left out (McQuown, 1981; Wyse, 1983), and the mother feels burdened, (Kung, 1981; McQuown, 1981; Stelle, Long, Reddy, Luhr, & Phipps, 2003). These feelings are reported elsewhere in the literature. The absent father in an intact family is a common characteristic in families dealing with a chronically ill child (Wyse, 1983). While the mother can manifest signs of anxiety and depression, the father will find reasons why he cannot be at appointments or be more active in treatment. The father's denial is his way of coping with his inability to do what he sees as his job—protect his family. Plus, he must deal with the ill child's siblings who may have their own problems.

This is a time when the marriage needs communication and where the relationship needs flexibility and openness (Bateson, 1978). Findings in the research literature show that childhood illness can increase parental vulnerability to depression and marital discord, though not necessarily into the clinical range (Wamboldt & Wamboldt, 2000). In addition, meta-analyses of numerous research studies suggest that the type, severity, and duration of an illness are not as important as family and parent variables and life stress in predicting emotional outcome in ill children (Wamboldt & Wamboldt, 2000). For example, research looking at childhood cancer patients and their mothers shows that coping and perceived adjustment in long-term survivors are positively correlated among other factors in relation to mother's coping (Kupst, Natta, Richardson, & Shulman, 1995; Brown, Kaslow, Madan-Swain, & Doepke, 1993). A strong bidirectional correlation is found between survivors' and mothers' adjustment.

The research has shown gender differences in how parents cope with the crisis of cancer. In fact, marital distress has been linked to these different coping styles (Hoekstra-Weers, et al, 1998). Fathers' distress was related to their own coping styles, not to that of their partners. Fathers used more active-problem-solving focusing on diagnosis and a less palliative reaction pattern than mothers. Mothers were more other-oriented, seeking more social support. Marital distress was related to their partners' coping preferences.

### **The Child with Cancer**

Because of the scope of this project, not all short-term and late-effects of cancer on the child can be specifically delineated. This paper provides an overview of main physical and cognitive effects on the child, and a more in-depth view of the psychosocial impact on the child and the family.

**Physical** A child undergoing treatment can experience many physical short-term side effects and late effects. Short-term effects include hair loss, nausea, vomiting, diarrhea, constipation, and pain from treatments and surgeries (Moore, 2002; Bearison, 1998; Adams & Deveau, 1993). Other short-term side effects from chemotherapy can include fatigue, mouth sores, and gross-motor coordination problems, such as limping. The lowered immune system response to chemotherapy can make a child more vulnerable to secondary infections like colds and the flu. A secondary concern for parents is that children can develop infections due to lowered immune systems. If a child becomes too ill, then he cannot have his treatment for the cancer.

Chemotherapy, radiation, and surgery can cause late effects involving any organ or system of the body (Hewitt, Weiner, Simone, 2003; Keene, Hobbie, & Ruccione,

2000). Most common physical late effects include those that are cardiopulmonary, endocrine (e.g., those affecting growth and fertility), musculoskeletal, and those related to second malignancies (Hewitt, Weiner, & Simone, 2003). The emergence of late effects depends on many factors such as age, exposures to chemotherapy and radiation during treatment (doses and parts of body exposed), and the severity of disease. In conversation with parents of survivors, it has been revealed that another late effect could come from a treatment decision a parent might have to make. For example, some major university hospitals participate in studies because they are continually trying to make treatments more effective, but less toxic. If a child is in a study, he or she may be randomly assigned this particular drug. This drug is often not for the primary cancer, but for a follow-up, “just in case” scenario. The research group may have discovered that the side effects of this drug cause more harm than good, but the group is not sure. For example, a given drug may make a child so anemic that in some cases, a child has died (Interview, Dr. Michael Link, 1988). The quandary for the parent is: stay in the study or not? Either way, the outcome for the child is not assured.

In recent medical history, families have had to deal with the fallout of social conditions when needing blood transfusions for the child. If the child treated for cancer before 1992 needed a blood transfusion, he might have been infected with Hepatitis C, Some children develop serious conditions from this disease (Keene, Hobbie, & Ruccione, 2000). Another worry for families until the mid-1980's was the possibility of getting a transfusion infected with the AIDS virus. It was ironic that a child could be cured of the cancer and then become fatally ill from the blood transfusion. Now, blood is screened well enough to avoid this fatal problem and terrible dilemma for parents.

**Cognitive** Cognitive impairments are prevalent and have the most debilitating late effects among children whose cancer or its treatment involves the central nervous system. A total of 50-60 percent of children treated for cancer will have some risk of neurocognitive impairment resulting from cancer and/or its treatment (Hewitt, Weiner, & Simone, 2003). Leukemia accounts for 30% of the childhood cancers, of which, the most common form is acute lymphoblastic leukemia (ALL) (Armstrong & Mulhern, 1999). ALL and brain tumors (20% of all childhood cancers) are the main cancers that tend to result in these neurocognitive impairments. Specific factors contributing to cognitive deficits include tumor characteristics (e.g., location and extent of the tumor), surgery (e.g., bleeding or infection), radiation therapy (e.g., dose, volume age at administration), and chemotherapy (Hewitt, Weiner, & Simone, 2003; Keene, Hobbie, & Ruccione, 2000; Armstrong & Mulhern, 1999). It is difficult to predict which children will experience some form of cognitive impairment, but certain factors are associated with a higher risk of problems. These factors include a younger age at time of treatment, the intensity of treatment, the duration of time between treatment and evaluation, and the age of the child at the time of evaluation. Gender is also a risk factor as the younger the female being treated, the more at risk she may be for a lower IQ outcome (Moleski, 2000; Armstrong & Mulhern, 1999). Extended absences from school due to treatment can also contribute to impaired academic performance (Moore, 2002).

These cognitive and neuropsychological impairments can lead to learning problems, social difficulties, behavioral adjustment problems, and long-term education and vocational difficulties. Cognitive impairments include declines in general intelligence and academic achievement scores (Moore, 2002). Neuropsychological deficits include

problems in attention and nonverbal memory, along with arithmetic, visual motor integration, sequencing, and verbal fluency (Hewitt, Weiner, & Simone, 2003; Moore, 2002; Moleski, 2000). These possible late effects, along with endured physical traumas and changes, can bring a child with different characteristics back to school.

**Psychological Effects** Issues affecting the whole family include attachment and post-traumatic stress. The former will be examined first in this section. Discussions will then follow specific to the adolescent with cancer, siblings, and then parents. This section will close with a discussion of how childhood cancer can leave members of a family with post-traumatic stress.

**Attachment** Attachments lie at the heart of family life (Byng-Hall, 1995, pp.45). Attachment is about relational bonds. An illness such as cancer can be disruptive to these relational bonds. Bowlby (1980) defines attachment behavior as any form of behavior that results in a person's attaining or retaining proximity to some other differentiated and preferred person. Attachment strategies are protective and adaptive. Exposure to danger such as distress, illness, hunger, fear, or strangeness, can activate the attachment system as the child will display attachment behaviors (Bowlby, 1982). Many of the most intense emotions arise during the formation, maintenance, disruption, and renewal of attachment relationships. Examples of attachment behavior are clinging, crying, calling, smiling, anger over an attachment figure's failure to meet the individual's needs and/or demands (Desmond, 1980). The status of a child's attachment to parents and the milieu of origin are crucial factors in stress resistance and vulnerability (Trad & Greenblatt, 1990). In fact, it has been found that a child with secure, supportive attachment to parents and with a home environment that is supportive and fosters respect for all family members is more likely to recuperate quickly from illnesses.

Currently, attachment theory has developed to include understanding of attachment patterns along with the adult's contribution to the adult-child dyad (Robson & Savage, 2001). Studies have shown that an adult's contributions to the adult-child dyad have roots in their own attachment history (Reder & Duncan, 2001; Kretchmar & Jacobvitz, 2002). Bowlby (1980) cites caregiving as a complementary function where the attached individual is protected. He says this is commonly shown by a parent, or other adult, toward a child. Bowlby continues to say caregiving from one adult to another is common in times of ill health. This caregiving from adults outside the nuclear family is also transferred to the attached individual, the child. Bearison (1998) discusses children coping with cancer. His stance is that children take their coping cues from their parents. He cites studies that demonstrate that children comply with medication protocols and cope with pain in a more positive way if parents are organized in their responses and appear to be adjusting well.

A family dealing with childhood cancer can be analyzed within an integrated construct of attachment theory and family systems theory. Desmond (1980) did an in-depth qualitative attachment study of two families, the Tandems and the Deacons. Both families were two-parent intact families, English-speaking, each with one child under the age of 16 diagnosed with the same type of cancer, ALL. By the end of the study, the Tandems' daughter had died and the Deacons' son was in remission. Her findings will be analyzed in terms of the attachment-family systems literature.

Desmond (1980) observed these families to see manifestations of attachment behavior and expressions (direct or indirect) of anger and anxiety. She was also interested

in any family communications about illness, loss, or death. The procedure included weekly home visits lasting about an hour and a half for ten weeks. The researcher used a tape recorder and written behavioral observations. Individual and conjoint family history interviews were conducted with the parents, assessments given to each person in the family, and then again eight weeks later. The same instruments were used both times and with each family member. The instruments were projective tests eliciting each subject's feelings about such issues as family interactions, how individuals see themselves in the family, illness, separation, loneliness, or isolation, body integrity and functioning or mutilation, denial or wish fulfillment, and death.

Desmond (1980) believed that one of the most important findings of her study was the clear demonstration of the necessity of understanding the particular character of a family prior to understanding the adaptation of that family to the crisis of childhood cancer. This finding is important because defenses are exacerbated during times of stress and defenses can often lead to distortions in perception and memory. The results of the interviews and testing indicated the four adults formed families with attachment bonds characterized by alienation and emotional isolation. When confronted with the possible death of one of their children, both their defenses and their emotional isolation were heightened. The parents perceived they were close knit because the families were in physical proximity, not communicatively interacting. The couples' feelings that the cancer brought them "closer together" was based on denial and avoidance of conflict rather than upon increased resolution of conflict or increased interactive collaboration. Testing for all family members showed isolation and the wish for more parental emotional support, especially from the fathers.

The families in the Desmond study are just one example of how families cope with childhood cancer in relation to attachment styles. Most often, the mother is occupied with the needs of the child with cancer and the medical care, while the father divides his time between work and the other children, and then, the child with cancer (Kung, 1981; Adams & Deveau, 1993; Keene, Hobbie, & Ruccione, 2000). This familiar pattern frequently observed in families with a seriously ill child is exemplified in a child's artwork (Copeland, 1983). In a picture drawn by a young child at M.D. Anderson Hospital and Tumor Institute, the child and mother are bonded together by the illness with positive and hostile elements. Siblings are engaged separately in an activity of their own, and the father is not shown in the picture, not perceived as a part of the essential family unit.

The family unit is coping with the cancer as a system (Kaplan, 1981). The attachment processes are in effect within and a part of the dynamic family system (Hill, Fonagy, Safier, & Sargent, 2003). Both the attachment process and the family system are working together to help the family adapt. The elements of the attachment processes referred to here are affect regulation, interpersonal understanding, information processing, and the provision of comfort within intimate relationships. These elements are also applicable in family systems with three added steps (Hill, Fonagy, Safier, & Sargent, 2003). The elements of attachment can be applied to the family using the concept of shared frames or representations of emotions, cognitions, and behaviors (Bateson, 1978). Second, individual and family processes can be linked. Third, there is a dynamic quality between attachment and other processes in family life. Hill, Fonagy, Safier, and Sargent (2003) call this an ecology of attachment within the family processes,

with ecology referring to the interactional and relationship context of attachment, and to the dynamic equilibrium of attachment with a wider array of interpersonal processes in families (p. 206). Families facing childhood cancer are faced with a disorder of change, a disturbance during which the family must come to terms with this upheaval (Kaplan, 1981). These families require help in adapting, where the result is an integration of attachment processes and family systems where a state of dynamic equilibrium is reached.

**Longing For Normality** Wanting normality is the deepest desire for most children with a life-threatening illness. Time becomes divided into two categories, the time before diagnosis and the time after. All children want the attributes of normality; regular, not special, ordinary, not exceptional, and to fit in, not to be different. The psychosocial effects of cancer depend upon the child's developmental level (Kazak, 1994). For this reason, issues such as impact of diagnosis, pain, hair loss, body image, and friends will be viewed in terms of adolescents. It is important to note for attachment purposes that hospitals now allow parents to stay with children of all ages. Children are isolated for very few procedures.

**Pre-Adolescence and Adolescence** Adolescence is a time to accomplish five psychosocial tasks: 1) develop a comfortable body image and positive self esteem; 2) create an identity through socialization; 3) establish emotional and economic independence; 4) form sexual identity; 5) develop goals for careers or employment (Zeltzer, 1980). Physiologically, it is a period of increased hormonal activity, and rapid growth, especially for boys (Adams & Deveau, 1993). On top of all these issues, girls have their own sets of pressures. Hinshaw (2009) calls these expectations the triple bind. In current culture, girls are expected to fulfill three criteria: be pretty, thin and popular; achieve in what were formerly male professions like medicine or law; and be a caregiver. A teenage girl is coping with cancer and still faces all these expectations.

Attachment relations in the adolescent years change as the family relations must change (Liddle & Schwartz, 2002). Adolescents need to remain connected to their parents while at the same time increasing their autonomy from their families and deepening their connections to peers of both sexes. These changes are interdependent and in tandem. Autonomy does not develop in isolation, but grows in the context of a changing but still close relationship with parents. This is supported by studies of nonclinical adolescents where positive relationships with parents support well-being and school adjustment (Cotterell, 1992; Steinberg, Darling & Fletcher, 1995).

One can imagine how a chronic medical condition like cancer can challenge the management of developmental tasks like autonomy, establishing close relationships to non-relatives and consolidating a positive self image (Salewski, 2003). Despite growing independence, parents are still strongly involved in the management of the illness, and the illness demands cooperation between the parent and the adolescent. The adolescent is conflicted between the need for his mother and his need for independence. However, an adolescent copes best when he senses cohesion in the family (Salewski, 2003), and when the family "... accepts the disease and you (Deasy-Spinetta, 1981, p.197)". If the family, especially the primary attachment figure, is coping well, the adolescent has a secure base with which to develop within the framework of this disease and its treatment.

Adolescents have many concerns. They worry. They may have had a grandparent who died from cancer. They realize they might die, that something that seemed far in the

future is now a present possibility. Bearison (1998) talks about adolescent compliance with medication. This can be a problem with teenagers. They feel like they have lost their locus of control.

Sexuality and fertility become issues ( Zeltzer, 1980; Keene, Hobbie, & Ruccione, 2000). Adolescents want to date, but some have had experiences of peers fearing they will catch something. Girls, especially, worry about fertility. When told she would lose a leg, a fourteen year old girl wondered “Will I get my period...am I still a woman (Zeltzer, 1980)?” Boys experience fertility related trauma. Anecdotally, one mother told this researcher that her thirteen year old boy had to give a sperm sample before starting treatment because the doctors were unsure whether the chemotherapy would affect his fertility.

There are issues with body image for adolescents. Hair loss is a significant stressor (Zeltzer, 1980; Copeland, 1983; Keene, Hobbie & Ruccione, 2000), especially since at this age, children want to fit in. Copeland (1983) states that, historically, hair loss has represented vitality, sexuality, and status. Therefore, an individual’s self concept is altered in many ways by this loss. The responses evoked by others contribute to a definition of self. An individual’s sense of masculinity or femininity is also threatened.

Studies have looked at body image and psychosocial adjustment in adolescents with cancer. One compared adjustment in adolescents with cancer to those with other chronic illnesses (Offer, Ostrov & Howard, 1984). The number included fifteen females and 12 males all still undergoing treatment. In this particular study, the cancer group had a normal self-image, with the males showing more sensitivity to impairment of their bodies. The study does not say there is no fear and worry, but that the adolescents in this study are coping with their fears and worries.

Another study (Pendley, Dahlquist, and Dreyer, 1997) looked at the same issue, but in 21 adolescents who had finished treatment. Cancer survivors reported many fewer social activities than those of healthy controls. No group differences were found on social anxiety, loneliness, or composite body image scores. Yet, within the cancer group, adolescents who had been off treatment longer reported lower self-worth, more social anxiety, and more negative body image perceptions, even though they were not rated as less attractive by observers. The researchers hypothesized as to why survivors’ negative feelings increase the farther out of treatment they are. Initially, these adolescents may experience a sense of euphoria after treatment ends, while positive changes are occurring, such as hair growth. After the first year of remission, they may start to compare themselves to healthy peers rather than patients and change their self-perception. Social support drops when treatment terminates and they may be lonely. Integrating back into the world of peers may be difficult. Some adolescents change their world view and have no patience for what they consider to be the “silly problems” of their friends. Others want to date, but are afraid. Some adolescents are afraid to believe they are truly cured, and go on with life on one hand, but hold back on the other.

**Late Effects** As survivors, children diagnosed with cancer at a younger age have been identified for developing mood disturbances at an older age (Hewitt, Weiner, & Simone, 2003). Cancer survivors have increased anxiety and depression as a consequence of perceived or real academic underachievement. Whereas children who experience chronic illness are at high risk for experiencing psychosocial adjustment problems, not all survivors of cancer have problems greater than the norm (Sawyer, Antoniou, Rice &

Baghurst, 2000). The determinants of individual outcome are complex and difficult to predict without considering multiple factors in the following domains: biological, psychological, and social stresses, along with changes in these arenas over time and at different stages of the disease and the child's development (O'Dougherty & Brown, 1990).

### **Post-Traumatic Stress**

Just as soldiers come home from war with "shell shock", survivors of cancer and their families find that their emotions are not "cancer-free" (Keene, Hobbie & Ruccione, 2000). When treatment stops, the family members have no more distractions. They are left to deal with the experience and what it means to their lives (Adams & Deveau, 1993; Keene, Hobbie, & Ruccione, 2000). The societal part of the problem is discussed by Saetersdal (1997). Parents with children with disabilities are supposed to "...function as good models (p.433)" for the community, playing Pollyanna. In fact, Saetersdal calls this the Pollyanna Syndrome. Rolland (1997) extends her argument by saying that in our social fixation for "the perfect healthy body," families living with illness must hide their suffering to demonstrate the value of their lives. He continues to assert that our societal ethos perpetuates a denial of death and suffering. Certainly, the media perpetuates the myth of eternal youth and beauty. For families coping with chronic conditions, it adds insult to injury to have the gritty side of their lives denied. The family is supposed to bounce back and present an "acceptable" image so that the outside world is comfortable.

These societal factors along with the psychological factors can lead to both clinical and non-clinical levels of post-traumatic stress disorder (PTSD). According the Diagnostic and Statistical Manual of Mental Disorders IV (1994), a diagnosis of PTSD may be diagnosed if the following criteria are met:

- The person experienced one or more events that involved threatened death or physical injury, or a threat to their own or others' physical integrity. These parameters specifically include learning that one (or one's child) has a life-threatening disease.
- The person's response included intense fear, helplessness, or horror.
- Other symptoms include hypervigilance, avoidance of traumatic reminders, recurrent intrusive memories or flashbacks, irritability, sense of isolation, problems concentrating, difficulty sleeping, diminished affect, and regressive behavior.

Childhood cancer consists of many traumas for the families (Kazak, 1994). The diagnosis is just the beginning in a long line of stressors. It is the author's observation that currently doctors believe in being extremely open, so they often tell school-age and older children their diagnosis very clearly. They then tell the children if they need surgery or tests to determine the extent of the cancer. Frequently, they tell them their chances of survival. It is extremely traumatic for a parent to have to hear their child being told what percentage of probability they have to survive. The process of the diagnostic evaluation is traumatic. It is current practice for doctors to call as they get results to tell a family if and where the cancer has spread. Older children are asked to be in on these phone conversations. The physical short- and long-term effects described earlier can be extremely anxiety producing.



Three studies examined posttraumatic stress symptoms in mothers and their children (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Kazak, Barakat, Alderfer, Rourke, Meeske, Gallagher, Cnaan, & Stuber, 2001; Brown, Madan-Swain, & Lambert, 2003). Barakat et al. (2000) examined the impact of posttraumatic stress symptoms (PTSS) in response to childhood cancer and treatment on general adjustment while accounting for the role of other stressful life events and appraisal of life threat and treatment intensity. The study assessed childhood cancer survivors, aged 8 to 18, and their mothers. The results demonstrated that PTSS in survivors of childhood cancer and their mothers are associated with long-term difficulties in adjustment. Stressful life events are also associated with long-term adjustment independent of the contribution of posttraumatic stress. The researchers found PTSS may influence one's general functioning. Life events most frequently and negatively endorsed by mothers are illness or injury of family members other than the child with cancer, separation/divorce, threat or attack to self/family member and change in work or financial situations. Life events most frequently endorsed by child survivors are hospitalization of parent, death of grandparents, threatened or hurt by someone, problems between parents change in parents' work situation and break-ups with a boy/girlfriend.

### **Special Education Law and Childhood Cancer**

The process for a smooth school re-entry for the child with cancer has been described above. However, public schools have legal obligations to provide appropriate education to children and adolescents with chronic illness (Clay, 2004; Keene, Hobbie, & Ruccione, 2000). There are three public laws that protect the rights of students with educational problems related to cancer treatment (Monaco and Smith, 2003): the Rehabilitation Act of 1973, Section 504; the Individuals with Disabilities Education Act (IDEA); and the Americans with Disabilities Act (ADA).

The Rehabilitation Act of 1973, Section 504, provides accommodations for students with any type of physical or mental impairment which can limit one or more major life activities or who are perceived as having this type of impairment. A chronic illness like cancer falls into this category. Any educational institution which receives federal funding is required to comply with accommodations which could include modifications in curriculum and the environment. The former could include the use of a calculator, more time on assignments, or a note-taker for a subject. The latter can include seating in the front of the classroom or being allowed to drink water during class.

The Individuals with Disabilities Education Act (IDEA), amended in 1991, and again in 1997 and 2004, includes a child with a traumatic brain injury or a brain tumor specifically. Prior to this amendment, children with either condition had to be classified as severely emotionally disturbed. Because of changes made to IDEA in 1997, the law now states that if a child with a disability qualifies for Special Education, that child does not have to be categorized or labeled by a specific impairment or condition. The criterion is that a learning disability exists, which interferes with the learning process, prohibiting a child from reaching his/her potential. Children with cancer can have a multitude of learning issues related to treatment, as has been described earlier in this paper. Therefore, these children are also eligible for "related services" by trained school specialists. Other services under this legislation include tutoring, specialized classroom placements, psychological services, adaptive physical education and transportation services. Parents

must initiate the process by requesting an evaluation for an Individual Education Plan (IEP).

The Americans with Disabilities Act (ADA) protects against discrimination in employment, transportation, communication, and government and public accommodations for people with disabilities. This means public schools, including higher education, must provide students with equal access to public spaces, events and opportunities. For example, if a child is in a wheelchair because of treatment, he/she must have access to a ramp or elevator to get to classes or events.

There are specific issues raised when a child has a serious health condition such as cancer. These have been addressed by the Community Alliance for Special Education (CASE) and Protection and Advocacy, Inc. (PAI). For example, if a child misses school in California for a long period of time, the child does not have to be eligible for any kind of special education or 504 services to receive individualized instruction or a home teacher, provided by the school district. If a child is in the hospital, out of his/her school district, the school district of the hospital must provide individualized instruction.

The parent must contact the school district and services must start within 5 days if the child is capable of receiving them. If the child is in and out of the hospital, and as a result, in and out of school districts, it can be very difficult for the child to receive services.

Another problem is the amount of time a child can receive services from the school district. If a child is not receiving any type of special education services, by law, the school can provide only five hours of instruction per week. This is because each hour is equivalent to a day of school and no child is entitled to have more than five days of school per week. This is related to receiving federal funding, as schools will not get money for more than five days.

However, if a child is eligible for special education under IDEA or is a Section 504 student, the program must be individualized to meet his/her needs. This means that five hours cannot be assumed to be sufficient instruction time. It would behoove a parent of a child with cancer to have the child evaluated for instruction under special education parameters. If the child does not meet the criteria for any kind of services, a complaint under Section 504 can be filed with the Office for Civil Rights in San Francisco (for example), if the parents live in the San Francisco Bay Area. This process could potentially be very stressful for a parent.

If a child has an individualized education plan, not just an identification as “Other Health Impaired,” the school team is required to meet every time there is a significant change in the student’s medical condition. For home instruction to be implemented, the team needs a report from the doctor verifying this necessity. Instruction is to be provided by a regular or special education teacher. If a student is eligible because of Other Health Impaired, specialized services may be provided such as individual consultation, home or hospital instruction, or instruction via communicative technology.

When a child returns to school after a long absence, under Section 504, if a teacher or the principal suspects the child may have a learning impairment due to the health issue, the school must have a system in place to refer this child for an assessment. A parent can also request the assessment. Some schools may offer accommodation promises, but not feel the necessity to write these down formally. CASE and PAI (2005) both encourage parents to have commitments in writing to avoid future legal problems.

There are other issues that can arise, but the ones presented here are the major educational issues for families. It is a goal of this study to see how schools are addressing these issues.

### **Re-entry to School**

The re-entry to school for children with cancer can be overwhelming because there are five major groups to consider: the child with cancer, the parents or other family members, teachers and school personnel, the ill child's classmates, and medical personnel (Prevatt, Heffer, & Lowe, 2000). School re-entry programs consider what these groups need when planning interventions to facilitate the transition back to school. There are reviews available for school re-entry programs (Worchel-Prevatt, Heffer, Prevatt, Miner, Young-Saleme, Horgan, Lopez, Rae, & Frankel, 1998; Prevatt, Heffer & Lowe, 2000), and a description of specific school re-entry programs (Worchel-Prevatt et al., 1998; Power et al., 2003). All re-entry programs plan with the same three systems, the home, the school, and healthcare, and in approximately the same three phases (Madan-Swain, Frederick, Wallander, 1999).

Phase I deals with initial hospitalization, or system preparation (Madan-Swain et al, 1999; Power et al, 2003). It is at this point that the family is encouraged to start at least thinking about school reentry. Some hospitals have special educators on staff to conduct educational assessments prior to treatment. Hospitals can also have teachers on staff if the child cannot go to school. Ideally, the hospital should keep the school informed of medical implications for learning. Parents are ideally supposed to contact the child's school, keep the teacher and classmates informed of progress, and encourage mutual communication between the child/adolescent with cancer and his or her peers. It is the time for school personnel to meet with the parents to plan for the child's return to school. The reviews cited above stress that the schools need to collect information from families about their psychosocial well-being during such meetings, including concerns related to siblings in the school system.

Phase 2 is the point at which education of school personnel should occur (Madan-Swain et al, 1999). Another name for this phase is system preparation/system integration (Power et al, 2003). Bessell (2001) says that teachers are in a position where they can either promote or discourage educational continuity for a seriously ill child. Yet, most educational professionals are neither trained nor emotionally prepared to deal with, or academically plan for, a child with cancer. It has been suggested have been made that the role of the school psychologists should include one of being an overseer for medically fragile children and children re-entering school after treatments for cancer (Armstrong et al, 1999; Power et al, 1999). Educational programs are conducted by hospital liaison staff to provide information for school personnel and students (Worchel-Prevatt et al, 1998; Prevatt et al, 2000; Power et al, 2003). The student with cancer may or may not choose to be involved in the presentation. These programs serve to demystify the disease and to normalize the situation as much as possible for both staff and students. These support mechanisms are supposed to help with peer relationships, absenteeism, and lessen adjustment difficulties for all parties concerned (Deasy-Spinetta, 1993; Sourkes, 1995; Madan-Swain et al, 1999).

Phase 3 involves follow-up in which communication is key (Madan-Swain et al, 1999). This phase is also labeled system integration (Power et al, 2003). By this point, Bronfenbrenner's (1992) mesosystems of family, school and the medical team need to be

interacting in a dynamic way. If the school understands the level of stress the family is under, it would be a great help to have a dialogue between the school psychologist and the medical team about absences, signs of anxiety and depression or fatigue. Thus, each system will function conjointly to promote health and the problem-solving process (Power et al, 2003).

As support, moral pedagogy (Sockett, in press; Sockett, 1993) and an ethic of care (Noddings, 1992; Gilligan, 1982) can make a difference in the ways schools respond to parents' needs. Sockett (1993) views teaching as primarily moral or dedicated to an individual's welfare and that the virtues relative to the process of teaching are congruent with personal virtues (Sockett, in press). In fact, the teacher must act in loco parentis, with the interests of the whole child at heart within a role constructed through a depth of trust between teacher, child and parent (Sockett, 1993). In light of this role, Nodding's (1992) view of caring is essential. She places caring as the basis of moral education and defines caring as a connection or encounter between two human beings. This study looks at the relationship of moral pedagogy as conceptualized and described by Sockett (1993), especially caring, and the school's reactions to the needs of parents.

Chapter One provided an overview of the study and states the objectives of the research.

Chapter Two reviewed the literature available about the effects of childhood cancer on the family system. The two models, the DoubleABCX and bioecological, are discussed regarding how they can frame the research hypotheses. The research on how parents have dealt with having a child with cancer, its affects on their marriages and the pressures on daily life are analyzed. The psychological and physical effects on the child with cancer is also presented followed by a presentation of optimum plans for school re-entry.

Chapter Three provides the background that led up to this study including a discussion of the pilot study and their preliminary findings.

Chapter Four focuses on the role of qualitative research, the participants in the present study, and the methodology employed in the study

Chapters Five and Six discuss the impact of the cancer diagnosis on a personal level, whereby parents and children with cancer, respectively, discuss their feelings on various topics. A discussion of how the diagnosis affected parents, their family life, marriages, and various issues underlying their lives. Finally, a discussion of adolescent patients with cancer describe their concerns, how they have coped with their cancer, relationships with peers and what they have learned as a result of their experience undergoing treatment.

Chapters Seven and Eight discuss the process of school re-entry. A description of the parents' reactions about their child's return to school, which school personnel were supportive and which were not, and how their child's experience was supported or was not. Parents informed the researcher how they perceived their child's back to school experience, how peers reacted, and how the child's siblings were treated. The children with cancer discussed what helped them succeed and what made their experiences difficult. They openly talked about how their peers treated them when they returned to school and if their physical appearance mattered to them.

Chapter Nine, the conclusion, summarizes findings. Findings are also compared to findings from the pilot study. The two models used to frame this study, the

DoubleABCX model and the bioecological model, frame the results of this study. In addition, analysis is done to ascertain if school personnel applied moral pedagogy and caring towards parents and children. A discussion follows about the implications of these findings in terms of educational policy and future research.

### Chapter 3 Background

A pilot study for this research was conducted in the fall of 2005. Four intact, Caucasian families, including seven parents in all, took part in this study. All were of high socioeconomic status with incomes over \$250,000 and college degrees. The children were ages 7-16 at the time of diagnosis. Treatment varied from three months to two and a half years. Each parental unit was given a demographic survey and an interview. Two of the four families were able to supply medical and/or educational documentation. After examining past research and conducting an investigation of the problem, an attempt was made to determine whether a match existed between the school reentry literature and the data that were gathered in this pilot study. Preliminary results of that pilot study guided this inquiry. Below, results are summarized. Multiple themes were found in the data. These include:

1. Diagnosis was a shock and life-changing
2. Children's reactions to their cancer were related to their parents' reactions and to their developmental level as well.
3. Children's peer relationships did not tend to be affected by the visible signs of treatment such as hair loss or being in a wheelchair.
4. Three of the four families saw long-term effects in their children ranging from health, fertility, and/or academic/vocational issues.
5. Two of the four mothers developed cancer later in life and related it to the stress of their children having cancer.
6. All parents reported closer marriages., even if there were problems prior to the diagnosis.
7. Gender made a difference in the style of parental coping. Mothers tended to reach out to family and friends while fathers focused either on their work or researching treatment protocols for their children's type of cancer.
8. Nuclear families reported that parents, siblings and the child with cancer drew together and became closer.

Three of the four families, who had boys with cancer, had negative experiences with the high schools they attended. It was reported that the schools did not facilitate re-entry according to the optimal phases or suggestions described in the literature review.

Overall, most of the themes in the pilot study were supported by research concerned with reactions to cancer, how it affects the interaction between members of a family, and how the child with cancer reacts over time with his/her diagnosis. However, most research does not discuss the effect of stress on the health of the parents or the reports that marriages had become strong . In the pilot study, one of the marriages was strained before their child was diagnosed with cancer and was later strengthened. It was reported that the diagnosis overrode the marital problems and pulled the marriage together.

This study encouraged me to do a more in-depth study on the subject of school re-entry with a higher number of families. First, the families to be studied had to be closer to the time of treatment, 5 years or less. It was essential to have more diverse families in terms of ethnicity, gender, socioeconomics, and family constellations. Another important component was to ascertain whether various learning abilities such as disorders of reading and written language, among the children with cancer, influenced the school-

student relationship and how principals and teachers perceived the quality of their interactions with parents and their child with cancer.

## Chapter 4 Research Design

### Research Questions

The goal of this study is to discover the answer to the main question: Are schools a stressor or a resource for families with children with cancer within the Double ABCX model and/or the bioecological model? Within these models, other important questions motivated this study: 1) How do parents and the child with cancer cope when facing school re-entry? 2) What do parents and the child with cancer want from school system in the way of support? 3) What are parents' perceptions of school support? 4) How do schools support the entire family?

### Participants

The parents were recruited from the San Francisco Bay Area through networking, support groups for parents of children with cancer, and by putting flyers in oncology clinics in medical centers. When parents had contacted the researcher via email or telephone, they received a phone call back if they had not reached the researcher in person.

The participants of this study were 17 families who have had a child with cancer, with a total of 23 participants (See Appendix D for demographics). Geographically, the families lived in Northern California, from the Sacramento area to Salinas. The number of participants interviewed included four married couples, 10 mothers, two fathers, and one adult sister. Of the 10 mothers, four were divorced and three were single parents. Two of the mothers were either remarried or living with a significant other. Four of those interviewed had their spouses and/or significant others complete the survey.

Participants	Interviewed	Surveys
Mothers	10	11
Sister	1	1
Fathers*	2	4
Couples	4	4

\*Includes stepfathers and significant others

With the parents' permission, 11 of the children, with varied types of cancer, were interviewed. The main selection criterion for this study was that participants had an adolescent child within 5 years of treatment and spoke English. The children were multiethnic adolescents ranging from seventh through twelfth grades (See Appendix D, Table 2).

Other participants included principals and teachers at the schools of the families with cancer. These educators were contacted by email or telephone with permission from the parents. In some cases, the parents contacted the principal and teacher. Each educator was told what the survey entailed and to expect the survey in the mail. Eight principals responded to the survey (See Appendix D). Twelve teachers/counselors, at the children's schools, filled out the surveys. An additional 2 teachers completed the survey, with 3 from one private school located in the San Francisco South Bay Area.

### Methods

The study described in this dissertation was fully approved by the Committee for Protection of Human Subjects at the University of California, Berkeley.

For this study, I used a mixture of qualitative and quantitative methods. Most of the data is qualitative in nature. Qualitative methods in studying families are used



because “the focus is not on identifying structural or demographic trends in families, but rather on the processes by which families create, sustain, and discuss their own family realities (Daly, 1984, p 4)”. Bronfenbrenner (2001) and others emphasize the importance of qualitative research which incorporates research designs that are generative (Bogdan and Biklan, 1998). Generative research means that findings are discovered rather than verified. In qualitative research, theory emerges from the data rather than hypotheses being derived from theory I selected a qualitative design, in order to further illuminate the phenomena of interest, the perceptions of parents, children, and school personnel when a child has cancer. My primary use of the qualitative method is consistent with the research of Cohen, Manion, and Morrison (2000) who believe that “ Social science is seen as a subjective undertaking as a means of dealing with the direct experience of people in specific contexts (20)”. It does not use numerical data.

Quantitative research uses numerical data. The Likert scales are examples of quantitative data in that they are ordinal measurements which allow people to make comparative judgments easily (Greenstein, 2001). I used quantitative data from Likert scales and surveys to support and triangulate the findings from the interviews.

### **Data Collection Methods and Procedures**

For in-depth case studies, data were collected in four ways: 1) parent and children’s interviews, 2) surveys from each parent used to collect demographic data, 3) a survey from each principal and one from a selected teacher where the child attends/attended school during treatment, and 4) a Likert scale that measured the parents’ satisfaction with the school. Forms, including the questions for the parent and child interviews, were sent to the parents ahead of time so they could be informed about the process. After the interview, parents were given the opportunity to add, via email or phone, any additional information they felt compelled to share after their interview. When appropriate, the information from one data source was used to supplement information provided by another. Parents were asked to bring signed consent forms and completed surveys to the interviews. Parents were also asked to bring copies of any medical, educational, or other documents applicable to the study. These could include class papers, letters by, or to, the child with cancer, correspondence from teachers, or special education personnel. Parents were told not to worry whether documents were relevant. The researcher examined the documents for relevance. Extra packets of surveys and other research materials were brought to the interview for parents who might have forgotten their packets. Demographic questionnaires were to be completed before the interview. If parents did not complete those beforehand, they filled them out at the time of the interview.

### **Measures**

The interviews were semi-structured and open ended (see Appendix B for interview protocol). Initially, parents were queried about how the family experienced having a child with cancer. For example, the parents were asked “How did this diagnosis affect your family as a whole?” Participants were asked such questions as, “What support was offered and/or given to you as parents?” and “Did the school personnel show caring for your ordeal as parents? If yes, how was this demonstrated?” Parents were given the opportunity to talk about issues that were most relevant to them. The importance of interviews is described by Ferguson (2008). These are called generated narratives that are

in-depth oral histories and semi-structured interviews conducted by researchers to allow a purposeful sample of families to tell their stories in their own words.

A demographic survey was given to parents of the child with cancer. The model for the surveys was developed at the Stanford Research Institute (SRI International, 2002) and was used to measure parent and instructor satisfaction and child success in every category of disability. Over six thousand parents and educators were surveyed in schools nationwide. This survey was developed for a national 5-year study, the Special Education Elementary Longitudinal Study (SEELS), that surveyed parents and educators nationwide using a random sample of schools and districts. Adapting the SEELS model for the survey in this study, the parent survey included questions about income, occupation, and health insurance. Other questions on the parent questionnaire (see Appendix B) asked about the parent-school relationship. For example: “Before your child’s diagnosis, what was your relationship with the school?” The parent was given a list of options from which to choose. Another question asked, “Did your interaction with the school change after your child’s diagnosis?” These responses were not numerically coded, but were reported categorically in tabular form (See Appendix D).

Surveys, also modeled after the SEELS format, were given to the principal and a teacher of the school where the child attends/attended. The principal survey asked demographic questions about the school. For example, principals were asked the number of students in the school along with the number of students who have had cancer during specified dates.

A Likert scale, included in the survey, was used to measure the parents’ satisfaction with school personnel. Each parent completed the scale with options to rate another member of the school staff of his/her choice. The teacher’s questionnaire (See Appendix B) included questions on a Likert scale such as “ This school provides support for working with students with cancer ”. The teachers were asked to select the answer that applied: 1 Strongly Agree 2 Agree 3 Disagree 4 Strongly Disagree 5 Not Applicable.

### **Data Analysis**

The surveys employed in the present study were adapted from the SEELS project described above. The surveys in the SEELS project were not psychometrically derived nor were they diagnostic. The advantage of using the SEELS surveys as models is that they were developed using an extensive field testing process that ultimately achieved clearance at the federal level. Items kept in the surveys were designed to be helpful to the user. Questions on these SEELS surveys have been used in other national surveys including the National Health Survey and the National Longitudinal Survey. Because these surveys were approved at the federal level and applied to other government studies, the researcher felt using adaptations of the SEELS questions in her surveys added to the reliability of her study.

The challenge of qualitative data analysis is to make sense of massive amounts of data, identify significant patterns, and construct a framework for communicating the main themes of what the data reveal (Patton, 2001). In this study, the interviews, surveys and the Likert scales were analyzed by the researcher with an inductive cross-case analysis. Inductive analysis means that the patterns, themes, and categories emerged out of the data rather than being imposed on them prior to data collection and analysis. A cross-case analysis means that the information was grouped together according to answers from different people, themes, perspectives or issues. Then, a content analysis was conducted

which includes the process of identifying, coding, and categorizing the primary patterns in the data. In the final step, the data was interpreted. Interpretation, by definition, goes beyond description. Interpretation means attaching significance to what was found offering explanations, drawing conclusions, making inferences, building linkages, attaching meaning, imposing order and dealing with rival explanations.

Qualitative data were explored in-depth to reach verifiable answers to various issues. Triangulation was used as a tool to verify responses. The data was able to be analyzed from different standpoints and, thus, findings were validated (Cohen et al 200). For example, analysis was done to determine if the information on the surveys confirmed information from the interviews. Did the school personnel's perceptions of their services reflect how the parents felt?

**Likert Satisfaction Scale** The Likert scale employed from the SEELS includes a 5-point survey sequence that measures parents' levels of satisfaction with school personnel from "Not supportive to Very Supportive". Once the interviews were analyzed, comparisons between the interview responses and Likert questions were analyzed.

### **Reporting Results: Presentation of Interview Data**

Each chapter, 5 through 8, is presented as a results chapter: Chapter 5, Results I: The Family and Cancer; Chapter 6, Results II :The Child and Cancer; Chapter 7, Results III: Parent Perception of the Schools; Chapter 8, Results IV: Children's Perceptions of the School. In the interview results chapters (Chapters 5, 6,7, and 8), interpretations are supported by examples of actual dialogue quotes. Interpretations are presented and then the quotes that support these interpretations are listed in easy to identify categories following the interpretations. Before the quote is the word Family, the family's assigned number, and role identification of the person interviewed. For example, a cited quote would be labeled: Family 1 Mother . These quotes have numbers listed after them (e.g., L6P79). This number represents where the quote was found in each participant's transcript. The number written above can be translated to mean that this quote was located on line 6, page 79. Some of the dialogue statements are not direct quotes; extraneous verbiage was eliminated to make important points easier to understand.

**Presentation of Survey and Transcript Data** Survey and transcript data are presented as evidence for the interpretations made from the interview data and as a consistency check for statements that were made in the interviews. This data is presented in tabular format in Appendix D.

**Privacy** Many families in this study were concerned with privacy. Extra precautions were used to protect the participants' identities. For example, in Table 1, a letter represents each participant's role, such as M for mother. Their roles (represented by letters) are not presented in any order, they are listed randomly. Later, the participants are given numbers that represent their dialogue quotes. To protect privacy, the letters that were assigned to certain individuals in the tables, do not correspond to the numbers assigned to the individual's dialog quotes later. In other words, Participant A in Table 1 is not Participant 1 as represented in the dialog quotes.

### **Rigor and Credibility**

**Limitations** Self-report data have limitations. Listed below are examples of problems associated with this form of information gathering:

- People often remember only the traumatic

- People color the truth to make themselves look better
- People forget important information
- People have trouble remembering information accurately
- People can give different testimony depending upon the interviewer, the time of the interview, and the environment.

Other limitations included the absence of a specific survey for counselors and the children with cancer. To account for some of these limitations, qualitative researchers are expected to be rigorous in the way they collect, code, and analyze data.

### **Interviews and Case Studies**

Within the positivist paradigm, a study's rigor is judged through measures of reliability and validity. Lincoln and Gruber (1985) offer four alternative terms for determining rigor of a qualitative study: credibility, confirmability, dependability, and transferability.

The responses to the interviews confirmed the rigor of the interview instrument. Usually, parents or the child brought up topics before the researcher could ask them.

Memory is considered problematic with any type of self-report study of events. In this study, to check for credibility, the interview data was cross-checked with information provided by the survey, and especially documentation. For example, if a parent remembered that no support was provided for the child at the school after their treatment, but their school records show that the child was given weekly counseling sessions with the school counselor, the result was differing perspectives between the school and the parents. Tables were developed which demonstrate the consistency or inconsistency between various data sources.

Some data analysis was confirmed by three outside observers who are not representative of the parents in the study. This means that three outside observers were given samples of the interview data separately, without guidelines from the researcher, to "analyze the data." The readers then read the manuscript and gave their impressions of the researchers findings. One reader has a JD, another has an MA in organizational psychology, and the third has an MA in speech and language therapy. This way, the researcher knew at minimum if the same data was presenting the same conclusions to three people who independently examined the data.

Dependability refers to the researcher's attempts to account for changing conditions in the subject chosen for study. There was reason to adapt the study as this is a study about events that have not only happened in the past, but are also occurring in the present. Overlapping methods used can corroborate and clarify data. The researcher took precautions against bias because of her own experience having a child with cancer. While analyzing the data, the researcher was constantly monitoring her own reactions to stay objective. Cohen et. al.(2000) asserts that both the interviewee and the interviewer bring "their own, often unconscious experimental and biographical baggage with them into the interview situation (120)". LeCompte and Preissle (1993) developed two terms, emic and etic. Emic means that the researcher must make every effort to understand the subjective meanings placed on the situations by participants. The term etic is concerned with the researcher's meaning and construction of the situations. Dependability means that the researcher can separate the two.

Transferability refers to the applicability of the findings to other settings, contexts, and groups. Generalizing findings was not the purpose here. The purpose was to

use the information gathered through multiple methods so that other researchers can explore data and determine the applicability of findings to their specific situations. Triangulation of methods through the use of multiple cases, multiple observers, and multiple sources of data, and multiple theories strengthen the transferability of the results of this study (Lincoln, 1988).

## Chapter 5

### Results I: The Family and Cancer

#### Reaction to the Diagnosis

It is not surprising that most parents describe themselves as being shocked, fearful, and scared. One parent was relieved, in a sense, because as a young child, his daughter was diagnosed with Fanconi Anemia. However, this is a DNA defect in the bone marrow which slowly mutates into cancer. This father had what Rolland (1990) refers to as “anticipatory anxiety.” The father knew this would happen, but he did not know when, and was relieved when it finally occurred. One of the mothers could only answer the “returning to school” portion of the interview because it was too difficult for her to talk about the family crisis.

Family 6 Mother: Oh, gosh. Um, I was shocked. I could not believe it. ..and it was scary because when you think of cancer, you just think of death. L18-19, P8

Family 3 Father: For me it's essentially, ... it's sort of relief. Because we know that she – in the long run, she would have a problem [She was born with Fanconi Anemia]. It's just like a bomb. You know, a time bomb . You don't know when it's going to go off. L13-15, P1

Family 10 Father: Well, it was, uh, shocking. ..the only action, the only hope I got was from her sister [For a bone marrow transplant]. I knew that she had the match and...we're hoping that a miracle would occur. So, that's my hope and, uh, you know, I want nothing else.

Interviewer: How did your wife take the news?

Family 10 Father: Uh, the same thing. She was crying. You know. as I said, our hope was our daughter. L1-7P2

#### Parent Perception of the Child's Reaction

Initially, parents were concerned about how to tell their children, which is another stressor for the parents. Overall, parents saw their children as strong with a positive attitude.

Family 5 Mother: And he [son] handled it well. He didn't cry, he didn't say "Why me?" He just was like, "Okay. We're just going to be finding out what to do." And that was it. L13-15P8

But, he did not want anyone to, baby him. L15P11

Family 11 Mother:...you see him so strong going through so many treatments.

Interviewer: So going from being so strong to, um,

Family 11 Mother: Learning how to live with his pain. L16-18P22

Family 12 Mother

Interviewer: Do you find it's just patience with other kids who... break an arm – do you find that he doesn't have patience with that?

Family 12 Mother: Nothing. I, I have a broken finger and every now and again I'll, 'cause I have to have surgery on it but I don't have time right

now. And so, every now and again I'll whack it and it'll bend and he'll be like "Oh, please. Don't even go there. No, you can fix that." Or a kid at school. Oh, one of the kids has pneumonia at school right now. And one of his good friends. He's – "Who cares. He's fine." There's zero tolerance. L22-24P26; L1-5P27

Family 12 Mother: That's the other thing. I would be in the next room studying, he's very belligerent, very verbally abusive, um, but he'll turn around and he'll be the sweetest thing in the world. It's just he doesn't know what to do with himself.

Interviewer: There's this anger.

Family 12 Mother: Yeah. Anger, frustration, disappointment, envy, um, jealousy. I can go boxing. He can't. L13-18P27F17M She thought it was a joke. L8P1

### **Perception of Support**

Many parents felt supported by their church, each other, and, in some cases, family and friends. A few parents felt support from their child with cancer because the child had a positive attitude.

Interviewer: Where did you find support?

Family 1 Mother: "with the support of our medical team and my parents" L14P15. "my husband and community support." L17P15

Because the community provided us with meals at the beginning L19P15

Well one thing I did – it would have been approximately a year after she was diagnosed and she was still in treatment, was I joined Team in Training which is the Leukemia and Lymphoma Society. L17-19P17

So that was very therapeutic for me. L24P19

Family 3, Father: Oh, I think the most important part for me to deal with this is my, my faith to the Christian belief. L6-7P2

They [people from church] are not doctors, they may not be able to solve the problem. They may not be giving even useful advice. But when they are with you, you know, you're emotional and your psychological, you get support. L5-8P4

I have looked for and been counseled. L18P5

Family 5 Mother: I have suffered from depression most of my life... I've tried taking antidepressants unsuccessfully in the past... And then when this hit, I immediately went to my general practitioner and said, "I'm going to need help." I had actually more of a...physiological response, which I've never had before, where when I would take my son to his test, I had sort of a fight or flight thing going on. ... And I just was aware that my coping skills were not going to be good and I couldn't stop crying,.. So I said [to the doctor], "Look. You need to give me something...But I need something that's going to help me to cope." L9-24P9

Family 6 Mother

...and A's [her son] attitude, um, is what got me through, you know.  
L1P41

Interviewer: What do you think is helping the two of you so you can go through this? What's helping you cope do you think?

Family 14 Mother: I don't know if you can call it coping, you just go on auto pilot and you do what needs to be done.

Interviewer: And that's how you cope with it right now?

Family 14 Mother: Yeh, I have a really close group of women friends, so I spend as much time with them as I can.

Interviewer: That's so important.

Family 14 Mother: Yeh.

Interviewer: Does your husband have friends that he can be with?

Family 14 Mother: He's got one or two friends that he hangs out with sometimes. L14-24P3

Family 17 Mother: ... asking a lot of questions and not being afraid to sound stupid to people. L23P22

### **Effect on Marriage/Relationship**

Most of the parents said it made their marriages stronger. Of these, some had marital problems prior to the diagnosis. However, their issues faded away as they bonded at this time of crisis. One set of parents were doing well at the time of the diagnosis, but as time wore on, their marriage became strained. Another parent went through a divorce. The marriage was in trouble before the divorce and the diagnosis only made their marriage worse.

Family 7 Mother: Um...and I think it pulled us stronger together. Um, I would like to say that our, our faith in God...helped pull us through but I think it was just our faith in humanity more than, than religion and the support that we have from the community. L16-19P24

Family 8 Father: Um, it goes back to, you know, being told day 2 of a child's life that they're special needs [Child has Down Syndrome]. And you have to, over time, cope with it, accept it, understand it. And it gave us a bond. Well we had one before, not to brag about our relationship but we did. And it also, over time, that also strengthened our relationship because we had to be a working team to be able to, not just with our son but for each other. How are you feeling today? How – asking each other...But because of having a special needs child that drew us closer together in 1988. So we were able to build from that coping with it. L15-24P10

Family 9 Mother: And, again, when you talk about coping, I think it comes down to just having that relationship that we share. L1-2P5

I'm just like, I feel like her disease is a thief and it keeps stealing and



stealing and stealing and stealing. And there's no control like...I want us to have husband and wife time, instead of parent time all the time. L8-11P5

...it did affect that relationship [Marriage to her child's father] tremendously. When he found out, he kind of checked out. Is essentially what happened. L17-19P6

Family 11 Mother: I got divorced.

Interviewer: As a result of this?

Family 11 Mother: As a result of this. Of course there were so many issues going in my marriage L22-24P2

Family 14 Mother

Interviewer: That was really good. How do you think this affected your marriage?

Family 14 Mother: Oh, completely strained it.

Interviewer: Oh, strained it... in what way?

Family 14 Mother: I wouldn't say, at first it didn't. We were pulled together, but it's four years later almost and his residual side effects and I just took another leave of absence from work and dealing with his low counts and then they're looking at removing his spleen and he feels terrible and he's depressed after treatment, so and that all falls mostly on me. L3-12P3

### **Effects on the Family as a Whole**

Often, the mother and the child with cancer form a dyad which can upset the attachment process of the siblings. Roles changed within the family. Some fathers had to be the caretaker for the other children in the family. Two fathers were the caretakers for the child with cancer, while the mothers worked and took care of the siblings. One stepsister, a senior in high school, was responsible for running the household while her parents and stepsister went to the Mayo Clinic. The sister admits to initially feeling jealous that her mother was not with her. A few of the siblings acted out or fell apart in school because their mothers were not available. Specific problems with other family and monetary issues will be discussed later in this chapter.

Family 1 Mother: Um, my husband and I divided our roles. My role was to be the caregiver for my daughter and then his role was to take care of the other three kids. So, that's how we handled it. And then my oldest daughter, um, she stayed in her room a lot during her sister's treatment. L21-24P21

So this is probably all he knows, right, ...? The 4-year-old? You know, would be having a sick sister L16-17P24

Because I was physically gone a lot, his[ brother, 7] concern was more about – when are you going to be home? Probably when am I going to get your attention? L4-5P25

Family 1 Father: Well, for me, I, I, took care of the other kids. More so than I ever did before. Because my wife was always taking care of them. And I was still working too. L22-23P50

Family 1 Mother: At the same time.

Interviewer: Wow.

Family 1 Father: So when I went to work it was like just being – for the first three months – it was just being numb. Just like, you know, all of a sudden there is more than work. There's life outside of work, you know. I mean it changes your the way you think about things. L2-7P51

Family 3-These parents had to take their daughter to the Mayo Clinic for her transplant.

The daughter's older step-sister took care of the house and other children.

Family 3 Sister It was my senior year in high school. The house was empty—I had to take care of the mail, 2 dogs, and the pool, putting in chlorine and chemicals, clean up the house, maintain the house, dishes. Luckily I got into a relationship with my boyfriend. He kinda kept me company.

... the family was pretty much able to take care of themselves. Here is the family: her 2nd oldest brother is the same year as me, both in high school. This brother is autistic. My stepsister's oldest brother is in college. My older brother is in college. My mom came back for my high school graduation. L15-24P1

Interviewer: How did this feel to you, as the one to carry the responsibility?

Family 3 Sister: I didn't resent it. I was scared—that's for sure because it was critical timing...

L1-3P2

This reminds me. When her dad and my mom had to give her attention I felt jealous; like taking my mom away because my mom is so loving. I was so jealous. That's my mom. She gives her best. Now I understand. L8-10P3

Family 3 Father

Interviewer: Okay. And how did that work [being in Minnesota] with your other children?

Family 3 Father: Yeah, that's difficult but we had support from the support group at our church. So people keep them in the house for dinner. And we also make a list. Day 1 with family, Day 2 with a family, so my son [autistic] can go to at least a different family every day for dinner or whatever. L6-11P3

Family 3 Father: He [autistic son] understands it. He understand that his sister has a very serious disease. I know my son very well – I explain to make him understand. ...I tell him ... a nice story, that he can understand that he can stay alone. So while we're out of the town in Minnesota, even if we are home dealing with my daughter who had been in hospital for several months, ... my autistic son – did a great job, he understands he needs to take care of the family. He's supposed to feed the dog. Take him for walk.

Interviewer: He did that?

Family 3 Father: Yes.

Interviewer: Wow.

Family 3 Father: Yeah, So I set up a schedule, all the tasks on a calendar for him with all of the resources. These ... our good friends, all their phone numbers. I train him to be this kind of agenda. And he took it. ...he says, okay, we have a sister in the cold. I have to do something...So every day he says that –dear father. you don't need to worry about me. I take care of the house. You go ahead take care of my sister. L6-23P25

Family 5 Mother: The diagnosis affected our family relationships. It created a strain between my ex-husband and I which felt very sad. I had expected that we would be able to completely put aside our differences, and rally together to support our son, but that was not the case. He was not very open about having his dad participate in his care, or stay with him at the hospital....My relationship with my boyfriend, who I live with, has been strained by the financial pressure and by my absence during treatment. I am dealing with a lot of emotions that have created distance in that he can't relate to what I've gone through. We are working things out, but it has had an impact. My daughter kind of "fell apart" emotionally as soon as my son completed his treatment. She had to go to therapy, and decided to be home schooled. L22-24P19; L1-9;20

Family 9 Mother: ....So it was just my daughter and her younger brother. And it really affected her brother because I didn't have a support system in place, so I pulled him out of school and home schooled him in his sister's hospital room. ...He ...didn't understand. He was 6 years-old. He made friends with other little cancer kids and their siblings. And so when his friends started to die, he was like, Where are they going? And so it became very clear to him, I could lose my sister. He went through a period of time where he grieved.. And, there were a couple times when he got really mad. He wanted his life back. L22-24P35; L1-7P36  
You know if you really think about it, there's two children that lost their childhood. L23-24P36

### **Plans Prior to Illness**

With one diagnosis, the lives of the families were changed. Families felt a lack of control. Plans were abandoned. A few families had trips planned, some parents were going to school, and others just wanted to continue with their lives .

Family 6 Mother: Um, okay, well, okay. Before he was diagnosed, I had been taking some courses in the National Alliance on Mental Illness. Because my, my, we're opening a room and board, uh, home for the mentally ill. L1-5P14  
It.... came to a quick stop, you know. (The mother choked up here.)L6-7P15

Family 5 Mother: I was enrolled in graduate school for my MFT license, which I was doing because of the kids being less needy, and more independent. We were trying to buy a house with the decreasing home prices, and generally, everything was going really well. The diagnosis shattered our lives in so many ways. L15-18P19

Family 12 Mother: Oh, it's totally different from, um, traveling to being spontaneous, to being super social, to being athletic and active, to, um, I mean me, too, I mean I am also, to, um, just life being as fun as you can make it. We have hit rock bottom L16-18P2  
So, life has changed dramatically from a really great life to a very homey lifestyle  
L24P2

### **Other Family Stressors**

There were other serious stressors in many of the families' backgrounds. One family lost a child to AIDS. Another family had a hydrocephalic child. One father had a family with extensive mental health issues and a child with autism. This family had to move from Taiwan because people with disabilities are shunned there. One mother was married and divorced several times so the family was uprooted every few years. There were so many extraneous problems that it was difficult to choose which stories to tell. In some cases, the fact that these people had already dealt with serious health issues both helped them through their crisis because they knew how to cope, and also made it more difficult stressors were piling up on one another. This pattern provides anecdotal evidence that stress creates or adds to existing health problems.

Family 3 Father: Yeah. Yeah. frankly speaking, at that moment, because everything comes to me, I have difficult at church, bad health of children, difficult ex-wife [schizophrenic] and her family .... You can see without the what we call quote on quote, the salvation from the lord, we could not survive. L19-22P4

The greatest thing I even thought about committing suicide quite several times because I think the life is painful. L24P4L1P5

I had a sister who die at age 23 of cancer. She is a lot inspiration for my life. Because of the last stage of her cancer, she very important, a lot to encourage me and is sad especially my parents not accept, a young daughter ok who die of this rare cancer disease. It age people, I see it age,

a fouled life...L1-5P11

Family 7 Mother: I should, um mention here that we were helped by - our first child's hydrocephalic. L19-20P3

So we actually have been through this process before, of having your dreams

shattered. L22-23P3

Family 8 Father: - what happened to us particularly with both my wife [brain tumor] and my son [Down Syndrome with leukemia] taking ill[at the same time] so quickly of each other, was the bottom dropped out. L11-13P12

Family 8 Father: [Tells about how his son saved his mother (via email, 6/30/10)]

My son was a hero for his mother. I was at school and our son found his mother passed out on the driveway. He called 911 and knew to go to a neighbor who is a nurse. He then called me and told me to come home due to his mom's fainting. When I arrived home, he had got the paramedics to the house and was helping our neighbor care for his mom. I know we gave you the news articles on this matter. He also received a commendation from Congressman Lantos for his quick actions and clear thinking in helping to save his mother.

This story was in the newspaper. His mother took it out to show the researcher. Their son asked if the researcher wanted his autograph on her copy. Of course, the researcher was very touched.

Family 8 Mother: Well I think with us too, because my mom went really quick, so we had my dad for so many years with the phone calls. And then -

Interviewer: It's one stress after the other.

Family 8 Mother: It is, you know, and it wasn't, I mean, you know, there's a lot we had to do for my father that we would never have wanted to do, either one of us...Then he was gone and it was kinda like, okay, you know, as miserable as I was over his passing and stuff, and then you know, life does eventually go on. And then it just seemed like, huh, now we're back to square one in a different way. But certainly something else hits you and, you know, we'd be moving along and then, something else hit us, I mean, so -L21-24P12; L1-8P113

Family 8 Father: Our daughter was at the time 24 or so, was diagnosed with severe cataracts. L14-15P15

Family 8 Mother: Well the best one was, even before the cataracts, she got sick in New York. And she kept telling us that she wasn't feeling good and she was down to, anyway to make a long story short, they ended up taking her to the emergency... ...she called me they'd admitted her to the hospital. They had no idea what was wrong with her. And they thought that she, too, had something wrong. And I could not go back. I couldn't. L17-23P15

Family 17 Mother: Um, my dad was diagnosed with bladder cancer the same week that my daughter was diagnosed with Hodgkin's lymphoma L6-7P27

Of course, my husband will have to speak for himself but, um, we had lost a child previous to our daughter of SIDS.

Yeah. We, um, we just weren't going to lose another. L6-9P21

### **Financial/Insurance Issues**

There was no question in the interview that when the participants were asked about insurance or monetary issues, many parents mentioned this as an added stressor. Interestingly, these issues were mentioned across all income levels. On the survey, parents indicated that the insurance had taken care of the expenses. However, in the interview, they talked about problems with the insurance companies and the worry about money.

Family 7 Mother: I do remember on for example, insurance. This was in the 7th week of her hospital stay when someone from accounting came up and said, "You know, you should have a talk with someone in billing because, uh, your insurance has a million dollar cap. And you've already accrued \$700,000. And I remember thinking, you go into another shock. I mean, this is week 7 of a 2-year treatment. You know and I, I called my husband and, and said – gotta check this out. You know. You, you have visions of your world falling apart...we've saved from day one, for, we always told our kids, you're not going to get your cars from us, but you're going to get a college education. College, retirement and you think, you could be, you could be wiped out. L17-24P5; L1-4P6

I think it was some lawyer someone recommended in San Francisco who knew about these things [insurance, monetary)...I remember him saying one of the options were, the guy told him we might consider divorce to try to save some of our options. And you know, I just wondered, we can't do that. You just feel so helpless. Your world's just crumbling ...L5-14P6

Family 9 Mother: ... And not only that [marriage problems, now remarried], but we lost our home. We lost our vehicles, because, insurance is not created or designed for a catastrophic illness L12-13.

Family 14 Mother: ...there's been a lot of strain because the school district was very uncooperative, we're really in the hole for medical expenses, therapy, lawyers. L3-6P4

I know it [the cancer] took years off my life and costs, we're strapped hard. L14P4

Family 15 Mother: ...there is a girl with the same kind of cancer that our son's been dealing with. ...she also had at least 2 chemo drugs and they're supposed to work in conjunction with his. ... put her in remission for 8 years. She's been in remission for 8 years with his cancer. L23-24P48

Family 15 Father: Can't get it through my medical plan L4P49

Family 15 Mother: And we have appealed to the State of California and everybody. And nobody's listening to us. And the last time we appealed, they told me this case is closed, don't call us anymore. L5-7P49

Family 15 Mother: The insurance company's not talking to us anymore.

Family 15 Father: My HMO, they won't talk about it anymore. L13-14P49

### **Concerns for the Future**

Parents were afraid of losing their child and/or the residual effects of the treatment itself. All were worried about the cancer returning. In the pilot study, there was a concern about fertility. None of the parents in the current study cared about fertility issues. They just wanted their child to survive.

Family 5 Mother: Of course the biggest concern is the fear of the cancer returning at some point. We had great results, and medically our prognosis is excellent, so we try to be in the moment, and not dwell on that. Evan has bilateral high frequency hearing loss, and has physical limitations due to his limb sparing surgery. He has a femur allograft, and will require several more surgeries in the future. These are concerns as well as the likelihood of arthritis developing at some point. L11-17P20

Family 9 Mother: Oh, what are we concerned about? Uh, quality of life.

Family 9 Mother: No. And we've been fighting for it for two years. And we've seen her steadily go backwards. She's gotten nerve damage in her brain. Vascular damage in her brain. ...Congestive heart failure. L115-22P28

Family 9 Mother: She sees a psychologist and a psychiatrist once a week. L24P29

Family 9 Mother: She's been diagnosed with major depressive disorder without psychotic features. L4-5P30

Family 13 Mother: All I care is my daughter to be alive. Because there is a lot of ways now to have children. Her sister may carry baby for her. I can carry baby for her. You saw that 61 year old woman who carried baby twins? I can do it for her. But I don't think that's what I think at all. The only thing I ask God to do is to keep my daughter healthy. L12-16P21

### **Discussion**

Clearly, these families have experienced acute intra-familial upheaval. The Double ABCX model is applicable to these parents' experiences with having a child with cancer. The interactive and additive nature of the primary event, the diagnosis of cancer, with all the stressors, upsets the homeostasis of the family. These families not only endured the devastating diagnosis that their children have cancer, but were overwhelmed by their everyday concerns. First, Factor aA in the Double ABCX model refers to diagnosis of cancer, the original stressor, and the pileup of other stressors such as financial issues. There are different demands depending upon the family member and his own ability to meet the challenges illness presents. The parents' own past traumas influenced their mindset along with the pileup of stressors. These families had a variety

of stressors past and present and are at risk for developing posttraumatic stress symptoms (Barakat et al. 2000). Because of this pileup of stressors, posttraumatic symptoms (PTSS) can impact the development of family equilibrium.

Factor bB is concerned with resources available to the family such as extended familial support, church groups, and medical services. Superimposed onto this life-changing illness, were the other issues these parents faced. Factor bB of the Double ABCX model was applicable because this is about how families see their financial resources. There was no question in the interviews that insurance or monetary issues caused a re-evaluation of resources. Interestingly, these issues were mentioned across all income levels. Barakat and Kazak (1999) emphasized that one of the major non-medical problems, when dealing with a child with cancer, is financial. The interaction with health insurance companies did not impact the child directly, but caused strain on the psychological well-being of the parents. This was an instance where the exosystem, a system outside of the family, in the bioecological model, impacted the child indirectly.

Factor cC referred to the parents' perceptions of the diagnosis, of their understanding of the demands, and of their own ability to manage their responsibilities. Parents knew they had to keep going and keep their families functioning. Parents may have been shocked by this catastrophic diagnosis of cancer, but for their families' sakes they knew they had to try to be strong for the whole family. Parents had to focus on their own relationship, their child's siblings, and worries about the future. Factor cC represented the parents' perceptions of the strength of their marriages, support from family and friends, and their religious beliefs. The perception of the quality of support outside of the family microsystem determined if the relationship between systems was bidirectional (Sameroff and Chandler, 1975). These parents also had to understand how work with another system, that of the medical field.

Factor xX is about how the family finally adapted to this illness and their other concerns. Families were concerned about their children's survival. Their state of mind is best described as the Damocles syndrome (Koocher and O'Malley, 1981). Metaphorically, these families were constantly hypervigilant. Further, they also carried with them what Rolland (1990) calls anticipatory loss referring to the fear of recurrence of the cancer and death of the child.

Factor xX is the final assessment of how each parent adapted to and managed this crisis. These parents felt they had worked hard to achieve balance within their families. The microsystem of the family was burdened by what the diagnosis brought them before interactions with schools were even considered.



Chapter 6  
**Results II: Children and Cancer**

**Finding Out**

These adolescents tried to adapt to their illness by being positive. Their responses were aligned with those of their parents.

Family 1 Daughter: Well, I, I asked if it was curable and they said, "Yes." So, I was fine. I felt like, okay then, I'll just take the medication and go through it. L14-15P1

Family 3 Daughter: Well I guess it was, I didn't really think about it at the time. I just thought it was live one day at a time. I guess I didn't, I mean it was overwhelming because I had to leave school and I didn't know if I'd be able to graduate or finish high school in time or just everything, and college and the future. And, also, I knew it was a really risky procedure [bone marrow transplant]. I didn't know if I would even survive. So, I mean, and I, I guess most of it that I was worried about was my friends and my family. L1-6P2

Family 6 Son: Yeah, I didn't really, like, wouldn't let it get to me. I said, yeah. Who cares if I have cancer. Like. You know. L8-9P45

Interviewer: But once you were in treatment for 3 months, then what did you think?

Family 6 Son: I was like, damn. Like, all this chemo's like getting me all like, tired out, weak, you know, and I'm missing school and I'm missing, um, my football and all that, you know. L12-16P45

Interviewer: So it really hit you then. So how would describe your emotions? L19P45

Family 6 Son: I was just like, I was really not letting, trying not to let it get to me or anything. So, I tried to keep a positive attitude, joking with the nurses and scaring them and all that. Pretending that I was sleeping and then "Aagh". L19-21P45

Interviewer: So first tell me, um, how did you feel when you were first diagnosed with cancer?

Family 12 Son: Um, mad and

Interviewer: Mad?

Family 12 Son: ...and then sad and then kinda like in denial. L1-5P1

Interviewer: What was the first thing that came to mind for you?

Family 12 Son: Um, that I might not feel the same again.

Interviewer: Okay.

Family 12 Son: Like, I may not be able to play sports again or, probably get better. L12-15P1

**Being a Teenager**

Cancer interferes with being a teenager and all it involves. At the time of adolescence, a teenager bonds with his/her peers more than with his/her parents. Some of the teens in this interview did try to rebel, sometimes with hospital personnel. Even

though some of the children were with parents for treatments, they still felt isolated from their peers. One young man was frustrated because the doctors did not want him to go home. Some teens felt they did not fit in anymore which was difficult for them.

Interviewer: Yes. So did you go through a rebellious period when you came back?

Family 3 Female: Um, did I? I mean I was just taking my medicine and, and

I wasn't supposed to be in the sun, because [it] attacks the thickness of your skin or something. L3-6P7

It was like, well, why can't I, why can't I do that? So I just sat out there kind of in rebellion. And just kind of frustration L14-15P7

Well I felt pretty alone and isolated physically and emotionally. So it was tough because I didn't know what they were doing and they were having fun at school and doing stuff that kids usually do and I wasn't able to participate because of my health. L17-20P3

Interviewer: Yeah, you didn't want people seeing you sick.

Family 6 Male: Yeah.

Interviewer: Well, I understand that. And I know guys don't really talk about this stuff. You kinda just play games.

Family 6 Male: Yeah, just try to be ourselves, be teenagers.

Interviewer: As a teenager, do you think your diagnosis affected your relationship with your parents?

Family 7 Female: Um, well certainly I became a lot more dependent on my parents. I was a lot more independent before and then I had to, particularly my mom. I had to really depend on my Mom for a whole lot of things that I'd been able to do for myself before and all of a sudden couldn't. L10-15P48

Family 9 Female: I can't be a teenager and....try to be around my friends and understand them. I don't know how because I don't know how to talk like them. I don't know how to be their friend because ....talking about their nails and their makeup and their hair...then they talk about, you know, for instance, oh, you know, I'm so horrible. Nobody is ever going to like me. This boy is never going to want to go out with me. You know, I'm just going to die alone. that's ... So, all I can hear is my friends complaining. And, so I'm on a totally different level.... and I feel kinda like an outcast... I'm all alone. Except when I'm either getting surgery or in the hospital, or, you know, coming to school. L11-23P21

I used to smoke and then my parents found out about it and then there was no more smoking. So, I stopped smoking and I got in trouble at school a couple times. ... I just finally stopped smoking. But the boys [her brothers] are allowed to smoke, but I can't smoke because of my heart. L12-15P33

Family 9 Female Written notes after tape: "At the end of Feb in 2009, I

was sick and tired of being sick and tired. Tired of everything. I didn't want to do it anymore. I tried to commit suicide. I was in St. Mary's ICU. The hard part was because I was so sick medically, I could not get into a psychiatric facility. My psychiatrist used my book. [written with her father in Texas]. It made me feel like I was making a difference.

Family 11 Male: ...like clearly, but I Yeah, to like get out of the hospital. I remember I was just there just thinking, I couldn't talk about it for a while ... And he [the doctor] just kept talking and I flipped him off... I just ...flipped him off. Yeah, to like get out of the hospital. I remember it like clearly, but I was just there just thinking, I couldn't talk about it for a while. L16-18P17

Family 11 Male: ...I want to be busy with school and sports. My friends come over and sleep over. I feel like a disconnection at home. I got lonely at home. L15-17P22

## **Friends**

Since adolescence is a time to interact with peers rather than with parents, these children had a lot to say about their relationships. Friends are certainly a resource for adolescents. Quite a few had one set of friends pre-diagnosis and, another set, post-diagnosis.

Of the 5 girls interviewed, 4 had to find another group of friends. All 6 of the boys kept their friends. The only boy who had difficulty had an early childhood diagnosis of Asperger Syndrome.

Family 1 Female: Uh, I felt like maybe I was like, like social changed a little bit. 'Cause I, um, my friends - in junior high they make new friends.

Interviewer: Yeah, right.

Family 1 Female: And they sort of hang out because they like separated and it was like – I don't know who to hang out with. So then, I think, what I know now I try to make friends with, like everybody. So I don't have like a specific set of friends that I always hang out with. L4-10P4

Family 8 Male: [Down Syndrome] I think of my poor friend [girlfriend] who had to eat her lunch alone because I am home sick.

Interviewer: Yeah that's sad because she was by herself.

Family 8 Male Child: Yeah.

Interviewer: I bet she missed you.

Family 8 Male Child: My friend, my friend looked after her. And my friend ate lunch with her. L2-7P10

## **Friends and Knowledge of Cancer**

These teens had to deal with their diagnoses and, then, the strain of the reactions from their middle school and high school peers. It is difficult for teenagers when peers find out about their illness. In some cases, some of the peers, in particular, passed along rumors about their peer's situation or were uncomfortable around them. However, some friends were very supportive.

Family 3 Female: Um, I still had another friend, this was in 8th grade. She had when she was. ...Also, it wasn't really cancer, it was a tumor. They caught it at the very earliest stage. So she was gone from school for a month, so she understood me the best out of all my friends. L21-24P10  
She knew that I had leukemia.... But when I got back, you know, she just didn't care about her health at all.

Interviewer: Oh.

Family 3 Female: She was still with the same people, but those people are not healthier, ...I understand her pretty well because I tried to tan and stuff like that, but she would not take care of herself and just fool around and smoke weed and - L1-7P11

Interviewer: Do you think your boyfriend understands your health issues?

Family 3 Female: He could understand to a degree, but I mean he can understand it physically but not emotionally. But, yeah.

Interviewer: Why do you say he's emotionally lacking understanding?

Family 3 Female: Um, I guess in terms of understanding of life as it is. 'Cause he's had a pretty, like, smooth life and not many complicated issues or anything like that. So, like it's harder for him to understand what I've been through or my family's been through...You know, so it's harder to talk with him about these thoughts. Like more meaningful, deep thoughts ...And, I guess, I mean, it's pretty hard. 'Cause like I wish he could understand, but I can't blame him for not. L1-12P12

Family 7 Female: My friends, I almost feel like my friends were more concerned about like treating me than like I was concerned about our relationship, like it would affect them...such a big thing, I mean, I was one day fine and it hit me so sudden.... And the next is like the word has gone around school that I have lung cancer, which I don't. But. 'Cause my lung collapsed so every-, like everyone's hearing like everything. Like I had 5 different types of cancer. And things were going around – you know how that works.

Interviewer: Yeah. So how did you get that clarified?

Family 7 Female: I guess like, things get out like, oh, she doesn't have lung cancer. It's okay. She's not going to die. L1-13P7

Interviewer: Did people come around and visit you?

Family 8 Male Child: Yeah, yeah. I have my teammates. My team was the Vikings.

Interviewer: So your team was the Vikings?

Family 8 Male: Yes.

Interviewer: Like what did you play?

Family 8 Male Child: They play high school.....

Interviewer: Football?

Family 8 Male: Yeah, I was the water boy.

Interviewer: Oh you were the water boy! How cool! L2-14P3

Interviewer: Your mom and dad said that you saw your class?  
Family 8 Male: Yeah. And they made a book from them to me.  
Interviewer: A scrapbook.  
Family 8 Male: Yeah.  
Interviewer: Wow.  
Family 8 Male: They made a book from the class for my birthday.  
Interviewer: For your birthday ...  
Family 8 Male: Yeah. And then a book that's... of Diana [Makes a heart shape].  
Interviewer: Oh...in a heart?  
Family 8 Male: Yeah in a heart. She said I misses my honey. L4-18P4

Interviewer: Okay. Do your friends understand that?  
Family 17 Female: No. Well, one of them does. And, she's just been the most very good friend to me ...I don't think she fully understands it. But at least she's attempted to. But my other friends, they don't understand it and they really don't, I don't think they want to understand it because that would kind of wake them up, you know, and make them have to get out of their world. And it sounds sad, but it's not. They just, they don't know. L17-24P3

As when I act in a way that my other friend doesn't like, um, I'll hear her [the friend] say, "Well maybe it's the cancer that's made you act this way." Things like that. L21-22P4

I had mixed emotions. Um, kids at the high school are really judgmental. So in the beginning I was kind of afraid of what they would think of me if I came back and I had cancer if I went back to school. .... And by the time the treatment was over then caring about my cancer really didn't matter that much. L4-8P40

### **Physical Changes**

Adolescence is a period of focus on one's body image. One young man had to go to school in a wheelchair because of effects of the cancer. He did not care. He just wanted to go to school. These teenagers responded with unexpected answers.

Family 1 Female: ...in junior high. That was when my hair was kind of funky. So, one of my friends that I met in junior high just thought I was like, doing a fashion statement then.

Interviewer: Well, what was your hair like?

Family 1 Female: It was like, I didn't want to cut it, so this part was like full, but then it was like real short and this part was thin.

Interviewer: Oh, so you never really lost all your hair.

Family 1 Female: Uh-uh. And then, I think 7th or 8th grade, then I cut that stringy part off and then just cut it short boy's hair cut.

Interviewer: Oh, must have been cute.

Family 1 Female: Yeah, it was funny. One time, like, the back of my head was facing someone and there was a group with all my friends that were girls and then she[the teacher] said "ladies and gentleman" 'cause she thought I was a boy. L6-18P9

Interviewer: So they know – you don't mind them knowing you don't have your hair?

Family 6 Male Child: Yeah, 'cause we talk, yeah, we talk jokes and all that, like my friend calls me Yoda ... so we joke at each other but we don't like, you know, like, - Oh, you baldheaded man – you know, and start cussing and all that. L10-20P52

Interviewer: Did anybody notice that you didn't have hair?

Family 16 Male: Yeah. I remember one time somebody called me skin head, like, they yelled that out when I was walking by.

Interviewer: So what'd you say?

Family 16 Male: Just ignored it. L15-19P4

Family 17 Female: So when I came back to the high school and I didn't have hair, I shocked a lot of people. Um, half the people that I know that were nice to me won't even talk to me anymore. I don't know why. I think, I think it's either guilt, or I don't know what it is. But most of the people that wouldn't talk to me before are now being nice to me and just saying hello when they never even looked my way before. And either they bugged me and it just doesn't now, but – people, it's like I've altered social groups at the high school. It's kind of interesting. L8-15P7

### **Philosophies of Life**

This section focuses on the emotional and psychological impact of having cancer. These adolescents had a different world view than their peers. The experience of having cancer acted as a catalyst for change about what was important in life and what was not. Some teens found it difficult “being normal”. As a result of the time spent battling their cancer, these adolescents had shifted their priorities and values from those of the group before they had cancer to those of their individual beliefs after treatment.

Family 1 Female: Um, well, I think I got a better outlook on life and, um, improved like my personality.

Interviewer: Tell me why you have a better outlook in life.

Family 1 Female: Well, I think, it's just a very quick second thought, but I thought like I wonder if God did this to me and I think, no he didn't. But then I thought – well, I might as well uses and then try to just see that a person, you know it's not a punishment, but use it as just like, if I was doing something bad, so I just start doing better things. L8-17P10

Interviewer: Okay. And, um, you said you wanted to be a better person and how, you said something else, how, um, how would you like your life to go? What do you see for yourself?

Family 1 Female Child: I, I want to be, I think a pediatric oncologist.

Interviewer: Oh, wow.

Family 1 Female: Yeah. And, but I'd like to get married and have kids. And there's this place called Camp OKizu.

Interviewer: Oh, sure.

Family 1 Female: Yeah. And there's a ropes course there and I went

there since I was 13. ....when I was 13 I first went on it and it was just amazing, like I really enjoyed it. Had a bunch of energy swinging through the trees and, uh, so, I think I want to also do that, um, with my career. Like, have a ropes course. Kind of set it near a hospital that I work at and like run it like a non-profit and get the kids to be able to experience that for free. L14-24P11, L1-4P12

Interviewer: So, is there anything else you want to talk about? Or things that you think people should know?

Family 9 Female: I don't know but we should just stop taking everything for granted. I mean, people do that a lot.

Interviewer: Yeah. They do.

Family 9 Female Child: I mean people complain about – even the line's too long, or being in traffic for instance...That is one thing that pisses me off. Because I can't drive, because of my seizures until they're fixed. And yet people complain that they're in traffic. They're just lucky they get to drive somewhere and get their selves from A to B. And, you know, parents. And once they see a kid with cancer they go - I'm gonna hug my kids and be so thankful that they're healthy. And it's like, you should do that anyway. Why does it take somebody, a kid with a bald head to tell you – ding-dong – you should love your kid more. L22-24P26; L1-14P27

Interviewer: What is your goal?

Family 11 Male: To go to college, university. Maybe looking after being a doctor. Something in the medical field. Maybe oncology and I can help little kids. Something in the medical field. L4-7P25

Family 17 Female:...Everybody else goes through life at the high school that I go to. They all go through life in their own little world. Concerned about what's immediately in their lives. And I've been forced to kinda open my eyes and look at the children that are, can't go to school and can't play be with the rest kids.

Interviewer: Uh-huh.

Family 17 Female: And, like I just kinda realize things that I never thought about before. Kids never think about the future. They think about the present and I've just kinda forced to think about the future. L9-16P40

### **Discussion**

Like their parents, children were shocked by their diagnosis and in some cases, the children were afraid they were going to die. However, like their parents, they adapted and tried to be positive. Both the Double ABCX and bioecological model provided frameworks to analyze these adolescents' replies. Their reactions to their illness are best framed by Factor aA, which is the introduction of the stressor event. Many of these adolescents spent a great deal of time in the hospital, a new system for them. They all felt very sick during chemotherapy which was an additional stressor.

According to child development, adolescence is the time for teens to move away from the family microsystem and align with peers (Zeltzer, 1980). In the case of these

adolescents, dependency upon their parents, due to their illnesses, interfered with their growing autonomy. These adolescents tried to adapt to their treatments, but still be teenagers with their peers. This adaptation illustrates Factor cC, accepting the stressor, and adjusting to both the internal and external changes from the cancer. The teens' views of their friendships were positive for some teens and more difficult for others. Many of the children felt isolated from their friends, which was a loss of a resource for them. Four of the five girls perceived that their friends, on the whole, were not resources, but people who had moved on with their lives. According to most of them, their friends had changed. These friends were on drugs or "in their own world". More of the boys, however, found their friends to be a resource. Their friends' knowledge about cancer was minimal, but these boys did not care. They were just happy to be with their friends.

Zeltzer (1980) also stated that adolescence is a time when adolescents develop a sense of sexual identity. It was noticeable that none of the children mentioned being in a romantic relationship except for the young woman in college and the boy with Down Syndrome. When the interviewer asked about having a boyfriend or girlfriend, all, except the two above, said they did not have a relationship.

These adolescents saw their bodies change gradually over time during treatment. All lost their hair and some lost quite a bit of weight. The responses to physical change, also Factor cC, were not what the researcher expected. It was surprising that their attitudes were mostly positive or at least adaptive. It was also interesting that a few of the boys did not want to go to school bald, but the girls did not care and went to school. If one of their peers was shocked by their loss of hair, many of these teens just shrugged this reaction off as the other person's problem. This casual attitude was especially unexpected with the girls. Usually, teenage girls feel they have to look perfect to fit in (Hinshaw, 2009), but because of their experiences fighting the cancer, they saw their hair loss as a small price to pay.

Another type of physical change was that many of these teens had chest ports inserted so that there was a semi-permanent place for the chemotherapy to be injected. Along with hair loss, this meant that these adolescents had a constant reminder of their illness until treatment was finished. One of the boys wanted to know if the researcher's son had a port also. He knew that the researcher's son was a survivor. It was clear that he wanted reassurance. The tone of his voice conveyed the hope that this would end and life would resume.

Finally, Factor xX refers to the children's adaption to their illnesses. Most of the participants felt they had matured and were better people as a result of their illnesses. Keene et al. (2000) asserts that many survivors and those who are going through treatment attest that having cancer opened their eyes. Two of the teenagers in this study wanted to become pediatric oncologists to help other children. It is the author's observation that this is not an uncommon goal for children being treated for cancer.



## Chapter 7

### Results III: Parental Perceptions of the School Experience

#### Return to School

This chapter reports parents' perceptions of their children's experiences when they returned to school. Of the 17 children, only 1 could not attend school. Of the remaining 16, half of the children had a positive experience, while the rest did not. The students who had positive experiences seemed to have these attributes in common: either the students were high achievers or the students were in special education. The parents' perceived negative school experiences if their children did not want to go to school for a variety of reasons including not wanting to be seen as weak, or not wanting to take medication at school. Negative experiences also occurred when there was a lack of cooperation between the parents and the school personnel. These circumstances arose when work packets were not prepared, when accommodations were not enforced, or when administrative staff were disrespectful to parents. Parents perceived positive experiences when teachers and/or the administration worked with the family and the student with cancer. Parents were appreciative when teachers sent cards from the class to school or kept in touch with the family.

Parents often had to be advocates for their children. Two examples of advocacy involved two different parents, a mother of one daughter, and a father of another daughter. The outcomes were different in spite of the facts that they both initiated and arranged a meeting with their child's school, and they were both from the highest income level in this study. Both sat down with the schools to prepare them for their daughters' re-entries. The father received what he needed from the school, while the mother had a mixed experience. Their impressions are written below.

Family 3 Father: [His daughter went back to school]...uh 2 months before she can graduate from the middle school. So, we, go to talk to the school, I go talk to the school. I don't want her to feel bad because she couldn't finish the school. She couldn't even have a middle school graduation, maybe certificate to show her status. It may be a little hard for her. But all her friends are going to the high school and she cannot. So I told the school. So I say people have heart, people always care, so the teacher in the middle school told me immediately that she would graduate. L7-14P12

Family 17 Mother: She was, um, we told her about 10 days ahead of time, to get her used to it. We notified her teachers that she was coming back. We had a meeting with the 504 coordinator who's the school psychologist, her counselor and her home hospital teacher. Um, to talk about perhaps the, the 504 and what her needs were and we got her in on it. They agreed to do a 504...

Family 17 Mother: Um, and to try to alleviate her fears for going back to school and we did that meeting. And also, we wanted to make sure that she knew what her classes were.

Interviewer: Uh-huh.

Family 17 Mother: Who her teachers were, where they were.

Family 17 Mother: Uh, things hadn't changed a whole lot because she left

school the middle of, uh, winter, the fall semester; and went back about 6 weeks into spring. Um, so, she tried to keep up in her classes and most of her teachers were very agreeable. There were some classes, like PE and drama, if you're not there you can't take the class.

Interviewer: Right.

Family 17 Mother: And I talked to her and I, I tried to counsel her and tell her that, you know, these kids are all in their own bubbles. They're all, all, life has been going on for them. You were there, you weren't there. Now you're going to come back. Believe it or not half of them aren't going to know that you were out.

Interviewer: How prophetic.

Family 17 Mother: And, you know, that's, so, don't stress about that. You know, you haven't lost or gained anyone probably. It's probably just gonna be quid pro quo or whatever the right word is. Um, she was, she was nervous and so I tried to alleviate her nervousness by meeting with the teacher, or actually shortening her school day. We got to have her go ..., so 5 or 6 classes, to have one at the home at home school class. And, uh, we met with her home school teacher ahead of time. Had her [home school teacher] contact the regular counselor, who's just swamped with 600 kids on her roster to have her have a schedule printed out for her for her first day of school and also to note the teachers she was going to have. Well she came back from that first day of school half, half or maybe not quite half, but a few of the teachers didn't know she was coming back...Several of them didn't know she was in their class, L17-24P29; L1-24P30; L1-13P31

### Likert Scales

The parents' responses to the interviews and to the Likert scales are in tabular forms (See Appendix D). The Likert scales can only be interpreted within the framework of the child's school situation, whether the child is still being homeschooled or is unable to participate in certain classes.

Below is part of a table of mothers' responses on the Likert scale. The complete tables are in Appendix D.

1=not supportive, 2-somewhat supportive, 3-average support, 4-very supportive, 5-extraordinary support, N/A-not applicable

English	5	2	-	5	1	1	5	n/a	1	4	4	5	4	n/a	3	4	5
Math	5	2	-	5	4	1	3	n/a	1	4	4	4	2	n/a	2	4	3
Science	n/a	1	-	5	5	1	3	n/a	1	4	4	5	5	n/a	2	4	5
History	n/a	1	-	5	1	1	4	n/a	1	4	4	5	5	n/a	2	4	5
P.E.	n/a	4	-	n/a	4	2	n/a	n/a	n/a	4	4	n/a	5	n/a	n/a	5	1
Classroom Aide	n/a	5	-	n/a	n/a	n/a	n/a	5	1	4	4	n/a	4	n/a	2	4	n/a
Principal	1	n/a#	-	++	++ +	1	3	1	1	5	5	5	4	1	3	4	2

The staff members of the two private schools were not rated any higher than some of the public school staff members. Where the results are marked “n/a,” the child was either unable to take the class or was unaffected by that particular category of personnel.

School personnel were rated according to how they had reached out to the parent and the child. Issues of trust or betrayal influenced the ratings. Special education teachers and the classroom aides were rated very highly. This reflected the relationships these groups of people had with the three children who had Individual Education Plans (IEP) before their diagnoses. Furthermore, these ratings mirror the findings in a much larger study measuring parental trust of teachers by Adams and Christenson (1998). That study included 123 parents of regular and special education students. Parents of students with “high trust” had children in intensive special education programs compared with those children with less intense special education plans. In this study, just because a child had a 504 plan, did not insure accommodations.

The researcher used information from the Likert scales and the surveys to determine if parent involvement with the school prior to diagnosis predicted their child’s success in re-entry to school. In the Adams and Christenson (1998) study, parents with “higher trust” also were very involved with the school. In the current study, the teacher surveys rated their perception of parent involvement, while, on their surveys, the parents self-reported their involvement in the schools (See Appendix D) Two teachers indicated that they did not know about the involvement of the parents. The rest of the teachers rated the parents as active in the school. However, it must be pointed out that these teachers were selected to fill out the surveys by the parents, and those parents selected teachers with whom they had good rapport. The researcher arbitrarily decided that if a parent was involved in five activities that the parent was very involved in the school. Before diagnosis, six mothers and three fathers were very active in the school. Two mothers were active in four activities. As would be expected, after diagnosis, involvement dropped for all but one mother and father. One father became more active with the school after diagnosis because he wanted his daughter to receive as much cooperation from the school as possible. Parent involvement did not reflect the level of accommodations provided by the school. The parents who had children receiving special education services rated the special education staff as extremely supportive, but indicated there was no relationship with the school as a whole. This observation speaks to the lack of integration between special education and general education. Some parents who only took part in parent-teacher conferences or only had interaction with the school if the teacher or principal called a meeting still received positive school support, while others with similar involvement did not. Some parents were very active, but the support was only fair, or even, negative. One mother labeled this interaction as “contentious”.

There are separate tables each for mothers’ and fathers’ overall ratings of Least Supportive and Most Supportive school personnel according to their interviews. These are meant to be compared to the table of the Likert scale ratings completed by each parent. For example, the mother in Family 1 said in the interview that the school nurse was very helpful, but did not write that on the Likert scales where there was a place to name “other.” The mother of Family 9 said the nurse was the most supportive in the interview, but did not list the nurse on the Likert scale. On the other hand, the mother of Family 5 gave a 4 on the scale for the technology teacher, but did not say anything about that teacher in the interview. The survey was explicit, allowing parents to rate the

personnel individually. An unexpected finding was that the school nurse played a positive role for the child returning to school. Five parents rated the nurse as exceptional during the interviews. Another surprising response was the reaction of the attendance office. Four parents responded that the attendance office was helpful, while 7 felt that the office caused them extra problems.

Teachers, counselors, and principals filled out surveys. The results of their surveys are in tabular form in Appendix D. Counselors filled out the teacher surveys by choice. Their data is included in the teacher tables. Fifteen teachers and nine principals completed the surveys. It is important to keep in mind that the parents selected which teachers and principals would fill out the surveys.

### **Support from School Personnel School**

Staff with personal experience with cancer or a serious illness were especially understanding of four of the families (Families 3,6,8,17). Where the schools were supportive, initiating help or reaching out to families, the parents felt the school experience was even more positive. Overall, eight mothers felt they had a very good experience according to their Likert scores. Yet, in their interviews, they quite often focused on the negative. Four fathers, out of the ten who rated the personnel, thought the schools were very supportive. One father, divorced from the child's mother, had no interaction with the schools and, as a result, could not rate school personnel. The counselor was seen as supportive by six mothers in both their interviews and surveys. Three fathers perceived the counselor as supportive.

In the case of one family, the mother and her significant other perceived the support differently from each other. She had two very low ratings, whereas her significant other had all very positive ratings. Her ex-husband, with whom she has a contentious relationship, actually rated personnel more in line with his ex-wife. Two principals, who were rated very highly by the mothers, indicated on their surveys that they offered a wide range of supports for their faculty and the families.

The two women below were on opposite ends of the socioeconomic spectrum with differing ethnicities. It was apparent that support, in this case, did not correlate with socioeconomics, gender or ethnicity.

This excerpt reflects both positive and negative support.

Interviewer: Was she his advisor?

Family 6 Mother: Yeah.

Interviewer: Oh, that's important to know. ...

Family 6 Mother: Yeah, and so, we actually sat down to talk about mostly. And then at that time, uh, she said...the advisor, you know, asked – oh, I brought up my son and about the home schooling and stuff and, and she was really, really surprised because he had been going good, you know, prior to his getting sick and injured...and she was just really, really saddened that they gave him all F's for the first semester.

Interviewer: Are you kidding me?

Family 6 Mother: No. All F's and, um, and the counselor, when she got wind of it, that, later on that day, she said, she, she called me, you know, I had left her a note also. She called me ... and she was just really, really, really irritated. You know, she said, she could not believe that no one ever told her that my son was out because she's the counselor. You know, if

she, she said that it never left the attendance office. You know? I was like, well that's weird because I have been talking to those teachers. I had let the coach know L16-24P19; L1-23P20

Family 8 Father: As far as the school was concerned, in my estimation, I'm sure my wife would probably have her own opinion, his teacher [Special Education] was fabulous and particularly one aide. Became true members of our family, there were times when they came here and stayed with him. They took him places. Very often they came and saw him in the office. There were times when they would bring students from the school to visit him in the hospital.

Interviewer: Wow I've never heard of anything like that.

Family 8 Father: There were times when they would bring students to the house, so our son wouldn't miss all his friends. So they were wonderful. Yeah. L15-24P17; L1P18

Family 9 Mother: Elementary and Junior High, they would work with her, work with us, as much as they possibly could. L16-17P39

Family 9 Mother: I can tell you in high school that, the school nurse, was the most supportive of anybody.

Family 9 Stepfather: It is the school nurse.

Interviewer: In what way?

Family 9 Mother: She was the one that would actually return emails, return phone calls. Be in constant communication. Always wanting updates on, you know, when she had surgery, she called to see how she was doing. From personal time, she didn't even call from the school. She called from home.

Family 9 Mother: Very caring, very genuine. And not afraid to ask questions and not afraid to say what she thought. If she was nervous about her being in school because of her seizures, she said something.

L24P40; L1-14P41

### **Lack of Support**

There was a discrepancy between the schools' perceptions of their support and the parents' perceptions. Five of fourteen mothers and three of eight fathers gave the principals very low ratings. Three mothers gave the principal ratings of being somewhat supportive to average support. Two fathers rated the principal as somewhat supportive and average support, respectively. Three of four couples, who rated the principal poorly, did not give consent for the principal to be given a survey. These parents firmly believed that the principal was neither concerned, nor even knew, about their child's illness. The fourth couple complained about the principal, but wanted the principal to be given a survey. Interestingly, this was the only principal who would not fill out a survey. Conversely, even if parents did not see the principal as helpful, the principal perceived himself/herself as offering a variety of services.

Three mothers and two fathers felt that teachers as a whole did not act supportively. The passage below sums up the frustration parents felt when they could not

get help for their child. The parent below did not feel respected, listened to, or cared for. There was a lack of collaboration, attentiveness, and communication.

Family 9 Mother: And I would like to see the school be more supportive of the students who are struggling. Who are fighting for their life. They give more attention to the kids who are committing misdemeanors and felonies L17-20P6 If they would take that same energy on the kids who don't care if they're at school, who are truant, off committing these juvenile crimes – if they put the same time, effort and everything else that they do into these kids into the kids who are chronically ill, who didn't go to a grocery store and buy their cancer, who didn't decide – hm- I don't want to go to school today so I'm just gonna go and, I don't know, smoke dope, or vandalize a park – if they just... these kids, we'd be so much better off. L24P6; L1-6P7

Additionally, the older sister of another child was exacerbated with the lack of attention because her school district has had 13 cases of leukemia in the last few years. She could not understand why the schools were not more empathetic. In her interview, she said that the vice principal and principal were not supportive. Yet, on the Likert scale, she circled “neutral” for both.

Family 2 Sister:

Interviewer: So, who showed you the least support in the school?

Family 2 Sister: Um, well, when we first went there, it was actually the assistant principal. You know, I just would basically kind of ask questions and he just kinda brushed us off.

Interviewer: Wow.

Family 2 Sister: Yeah, and, uh, so he wasn't very helpful at all. And, you know, I was just kind of inquiring what services they had for him, obviously I didn't plan on saying that he had cancer, but

Interviewer: Uh-huh.

Family 2 Sister: I was just kinda, you know, asking just to figure out you know, what we could do to help him transition to this other school, 'cause he was actually, uh, starting school a few weeks late already.

Interviewer: Right. Right.

Family 2 Sister: But, yeah, he just kinda brushed us off and I never actually met the principal, so.

Interviewer: That is so bad. I mean really bad. What do you wish they had done?

Family 2 Sister: Well, I wish that they had been a little more concerned. Obviously I know that they're busy and they have a lot of things that they need to coordinate but, you know, it's like to kind of brush us off without even hearing us out. I had said that I was so concerned about him going back to school. L13-24P10; L1-13P11

Family 15 Father: But as he gets older, the resources are not there and it's hard because, even I have commented to our social worker, that I kinda

resent the fact that they put him on a back burner, and not given him the resources that are due.

Interviewer: And you mean the school?

Family 15 Father: The school. I'm talking about just the system in general, how they look at older -

Interviewer: You don't mean older kids in general. You mean older cancer patients.

Family 15 Father: Yeah. L18-24P23

### **Hospital and the School**

These two entities, the hospitals and the schools, were supposed to interact to benefit the parents, the child, and the school. When the hospital stayed in touch with the school, the educators could more effectively plan for the child's return to school. Even more, the school could understand more clearly what the family was going through and what the family needed. Positive interaction between the hospital and the school was also a relief to parents who already felt overwhelmed. The hospital and the school worked together for 8 families. The hospital got in touch with the school for three of the families, but the school did not follow through. Where the school and the hospital collaborated successfully, the parent said it "helped to make life easier (F11)". Of the 17, two parents did not want any accommodations.

Interviewer: How did the school and hospital personnel collaborate?

Family 4 Mother: Hospital personnel helped us to coordinate taking AP/SAT tests on-site. L23-24P1

Interviewer: Did the school or hospital inform you about services available for your child according to Special Education law?

Family 16 Mother: No, not really. That was it. L1-3P17

Family 17 Mother:

Interviewer: Um, who told you about special ed law and accommodations? Was this the hospital?

Family 17 Mother: Uh, with the HEAL program at Lucille Packard.

Interviewer: Okay. She told you.

Family 17 Mother: Yes, yes. And she actually worked as, worked as a liaison with me and the high school. She got a hold of the, the district psychologist.

L13-18P35

### **School Accommodations**

These parents wanted the school to be adaptive to their child's needs. Often, families did not know they were due accommodations by law, while at the same time, schools were unsure how to help these families. The schools coped in three ways: they used special education law to help the student, they made a show of support by agreeing to implement accommodations, but had no follow-through, or they offered no accommodations at all. This last strategy worked if the parents did not know their rights. In return, families helped by being open to what the school offered. Of the seventeen families interviewed and surveyed, only 5 families had appropriate accommodations according to parent report. Two of these families had a child with an IEP already. Three

of the seventeen families had 504 plans which were not followed. Of the twelve remaining families, four of the children did not want any special treatment. The other families were not aware that they could have services.

Overall, the principals' perceptions were opposite of those of the parents. All the principals marked that they offered at least two services and that all general education teachers received some assistance. Only two principals (F4, F14) indicated that their teachers had some training to work with students with cancer. However, the data from the teacher surveys showed that those teachers did not receive any training. It is evident that not only was there miscommunication between the school and the parents, but there was also internal miscommunication within the school itself.

Family 1 Mother: At first, this mother said there were no plans on paper, that she "wasn't educated about it at the time so I didn't know anything about it." L1P30

Um, well she [the school counselor] helped with modifications as well. But she didn't recommend the 504 plan until she was in 8th grade.

She even said something like, I'm not sure why we didn't do this earlier but she just thought of it in 8th grade not 7th. Even though it was the same person.

She also needs to drink water...[School counselor] had requested her memory skills to be tested, to be assessed, which they, the school didn't provide -

Interviewer: Really?

Family 1 Mother: Yeah, she just like never got back to us. So the, uh, Lucille Packard did the test -

Interviewer: Oh, well, that's good.

Family 1 Mother: So almost a year after we requested it.

Interviewer: Oh, my gosh.

Family 1 Mother: She just came up, the lady that assessed her, I mean that did the 504, she just like, I'm really busy and I said, okay.

Um, I think she could have handled this differently.

Interviewer: How would you have liked it to be handled?

Family 1 Mother: Well, I would like for my daughter to have gotten the testing through school, the cognitive testing,

Interviewer: Right.

Family 1 Mother: Because she even had written down there – [counselor] has requested that her memory skills to be assessed and it never happened.

Family 1 Mother: Yeah. It's the school psychologist – looks like she's on here. L16-17P31; L19-20P31; L11-23P32: L1-9P33

Interviewer: So how did you learn about all the rights - the special education laws as it pertains to having cancer? Because there are special education laws for that.

Family 15 Mother: Right.

Interviewer: Now, did anyone tell you about those? Do you know about them?

Family 15 Father: We've been learning about various things through the



internet. And through social services department.

Interviewer: When you say, internet, social services - you mean

Family 15 Father: At Children's Hospital.

Family 15 Mother: Children's Hospital.

Interviewer: So a social worker told you that?

Family 15 Mother: Yes.

Family 15 Father: They told us some things and also our son's therapist, who happens to be a woman who deals with the school system and the children that are going through these various diseases. She's actually an advocate.

L12-24P22; L1P23

Interviewer: They're [the teachers] supposed to provide outlines for them - it's hard for these kids to even take notes.

Family 15 Mother: Exactly. At one point, they assigned someone to do that but that kind of went by the wayside.

Family 15 Father: They were going to give him a microfiche, the overheads.

Family 15 Mother: That never came.

Interviewer: And you tried to get that. Was that on IEP?

Family 15 Father: Yeh, it's on IEP as far as helping him with information, getting the information he needs in order to work on projects. Even now they've made it, 'cause he has 4 classes, he can actually get assistance in the learning center on projects.... He has to initiate this in order to do it.

Family 15 Father: Right, and the school isn't going to initiate because they're going to feel like he isn't. L20-24P35; L1-13P36

### **School's Knowledge of Cancer and Effects**

Part of the importance of the hospital and the school working together is that the school can be educated about cancer, what a family might need, and how to plan an optimal program for the child. Lacking communication between the two, these schools knew neither what supports the family needed nor the effects of cancer on learning. It is crucial that schools learn these effects because Kazak et al. (1994) report that only 25% of their sample of long-term cancer survivors received special school services related to learning problems. The need for the availability of special education for this population becomes clear when one considers that almost 30% of adult cancer survivors report having academic difficulties (Lansky, List, & Ritter-Sterr, 1986). In the current study, the only school personnel who understood what it meant to have cancer also had family members who had cancer or a very ill child. From the parents' interviews, 14 out of 17 school personnel did not understand what effects cancer had on learning.

Overall, the teachers perceived themselves as able to work with a child with cancer (See Appendix D). This clashed with what the parents said in their interviews. In one case, the parent spoke highly of the art teacher and rated him highly on the Likert scale. The parent felt he was empathetic, in part, because this teacher had a child who had been very ill. However, on the teacher Likert scale, this teacher indicated that while he was comfortable working with a child with cancer, and received support from the school, he felt very limited with his ability to work with a child with cancer. He also did not have any in-services on this topic. It was the opposite with other families. They thought the

teachers did not know how to address the needs of a child with cancer, but the teachers did.

Interviewer: Okay. So do you think that any of them understood what it meant to have cancer and the effects that could occur in learning?

Family 1 Mother: I kind of got the impression through our experience with the school that our daughter possibly could have been the first student with cancer.

Interviewer: Okay...so do you think the school personnel knew anything about cancer and treatment?

Family 2 Sister: I really don't think so, but considering that there's so many ill children from this area that get this type of cancer, you'd think they'd be a little bit more understanding.

Family 15 Father: And I went up to O. High School and I said, "This is what's going on." And they said, "Well, you need to understand your son's case is very unusual and the whole time that we've been running the school we've only had a girl who's been in a bad crash, we've never had someone who's going through carcinoma like yours so, so we don't have anything to compare it to." So they don't have -

Interviewer: So they were unfamiliar.

Family 15 Father: They're very unfamiliar with what to do in this situation.

L13-20P32

### **Learning Issues/Late Effects**

Education is affected when a child develops learning problems or health problems as a result of treatment. In this study, five parents reported that their children have or have had memory problems, short and long term. Word retrieval was a problem. Quite a few had decreased ability in math. The child with Down Syndrome had an increased deficit in speech articulation as a result of his treatment. However, the school system would not add speech and language therapy to his IEP. Three children had health problems as a result of the chemotherapy. One had to have a hip replacement, another developed seizures and chronic heart failure, while the other had an enlarged spleen.

Four principals checked that they gave general education teachers in-service training on the effects of childhood cancer. Not one of those teachers said they had received this training. All principals indicated that special education personnel consulted with the faculty. Neither teachers nor parents agreed with this statement. The only time special education teachers worked with a family was when the child was actually receiving special education services. Again, data revealed that there were differing perceptions regarding learning issues.

Interviewer: Did the school understand the cognitive effect or any other kinds of effects that cancer can cause in a student? Student's learning, or.

Family 12 Mother: Uh, I would say no. Just because it's so rare. It's just, he's such a young kid with cancer, um, but because of the communication we had with the hospital, my husband was, um, able to relay it to the school . L15-17P17

Family 17 Mother: ...she would cover all the work with less assignments, more time to do those assignments, a little bit more time to do the testing, um, because it, it, she says [she has a hard] time [with] her skills. She has a little memory problem at this time, challenges at this time.  
L19-22P21

...but her math and memorization seemed to be really affected.

Interviewer: Okay. And are they, is anybody helping her with that?

Family 17 Mother: We've hired a tutor to help her with math.

L9-12P32

### **Peers at School and Cancer**

The culture of typical high school peers is discordant with the culture of children with cancer. The values, language and behaviors of the two groups are different. Adolescents can develop their self-images from interacting with their peers. Their values are the group's values (Liddle & Schwartz, 2002). However, when a child has cancer, these peers often no longer reflect the identity of the child. The adolescent with cancer is concerned with survival.

According to their parents, ten of the seventeen children had positive experiences with close friends. The parents did not think these close friends understood what having cancer meant. In addition, the parents felt their children were uncomfortable with those outside of their child's circle. Support was given through phone calls, texting and emailing. A few of the children's friends came to the hospital. The girls who were outstanding students were welcomed back to school with enthusiasm by their peers. These girls were not caught up in the triple bind (Hinshaw, 2009), that is, simultaneously trying to be caretakers, beautiful and popular, and high achievers. Prior to their illnesses, these girls focused on grades and school activities. However, they did not date nor were they consumed with their appearances. In other cases, the experiences were positive because the children with cancer were not self-conscious about the visible reminders of the disease. Seven had very difficult interactions. One teacher did not believe that the child had cancer. Peers told the returning students they thought the student had died. Many peers were insensitive and/or had started using drugs. Other peers thought they might "catch it" if they went too close to the child.

Family 9 Mother and Father: Right. So this is how high school girls work. While they were at their big group dinner before Junior Prom, they started making bets on if our daughter would have a seizure or not that night at Junior Prom. They thought it was funny. And this is the girl who, you know, "Oh, I'm your friend. I'm there for you."

Interviewer: Is this [a specific friend]?

Family 9 Father: Yeh. But then, turns around and does this.

Interviewer: Was your daughter there at the dinner?

Family 9 Father: No.

Family 9 Mother: She had no clue about it until just recently.

Family 9 Father: Just recently.

Family 9 Mother: She [daughter] had actually texted [her friend] because she hadn't called her or text her for quite some time and said, "Hey, how's it going?" She said, I'm surprised you're even talking to me,

hiding behind the vice principal and all. 'Cause we'd gone to the vice principal and said, "Hey, this is what's going on." And we didn't want to say anything to her [daughter] until we'd gotten some kind of answers from the school as to what they were planning to do about it.

Family 9 Father: Because it was a school function.

Family 9 Mother: And we never got any answers.

Interviewer: Did she go to the prom?

Family 9 Mother: Yes, she did. L18-24P55; P1-13P56

Interviewer: Do they [her peers] understand what it means?

Family 13 Mother: Yes. Some of them come to the, you know, one of the, one of her friends came to, came to Stanford to spend the night with her.

L13-15P24

### **Siblings and School**

When a child has cancer, siblings need to be cared for because they lose the close attention of their primary caregiver, who is usually their mother. Siblings in college and/or away from home were not as affected, in this study, as siblings still at home. In this study, an older sister (F1, F3, F5) either self-reported, or parents remarked, that they had a very difficult time either in school or at home. The younger brother for family F9 needed to be monitored by the extended family to stave off serious problems. The researcher found that older brothers had a difficult time if they went to the same high school or were out of school and still living at home (F2, F17). The younger brother of F13 found support from his teacher. There were four families where the school-sibling relationship was not applicable because the child with cancer was an only child or the siblings no longer lived at home. Five siblings did not have support from the schools. Six siblings had positive experiences because they were either in special education or their parents had informed the school about what was going on in the home. This latter cohort had meetings with the teachers. Two parents did not know if the siblings' schools knew. The onus of communicating with the schools and making sure they were following through was on the parents.

Interviewer: Okay. So were there any kids [siblings] in high school when he was going through this?

Family 2 Sister: There was our other brother.

Interviewer: Your other what?

Family 2 Sister: Our other brother.

Interviewer: Oh, right.

Family 2 Sister: At that time, yeah.

Interviewer: Did it affect him and his behavior?

Family 2 Sister: Oh, yeah. It definitely affected him a lot.

Interviewer: What happened?

Family 2 Sister: Um, he was just very moody. He was very, he was cutting class, he was failing classes. He was very angry at the world.

Interviewer: Wow, but did his teachers know what was going on?

Family 2 Sister: Um, some of them did, those he was close to.

Interviewer: Uh-huh.

Family 2 Sister: But others, you know, had no clue.

Interviewer: So, what do you think you would have liked to have happen in your brother's school?

Family 2 Sister: Um, you know, I really don't know.

Interviewer: Um, 'cause you're probably so busy, how did they know about his [brother's] cancer? Did you tell them or did his brother tell them?

Family 2 Sister: I think his brother was the one that told some of the teachers. My brother ... a lot before he tells certain information, so for him it was the teachers that he was close to knew that was going on. But, you know, he's not close to all his teachers.

Interviewer: Well, did you, ...did any of them notice that his grades had gone down? Did they associate it with, ... his brother's illness?

Family 2 Sister: No. They just associated it with, you know, just him cutting class and not wanting to finish school. They just didn't really know what was going on with him.

Interviewer: Right, right. So he really had a rough time. Um, it sounds like the school didn't do anything for him. I mean if one teacher knew about it, I'm surprised he or she didn't alert the, um, the principal, counselor and, you know, the other teachers.

Family 2 Sister: Right. L24P14; L1-24P15; L1-9P16

Interviewer: So would you say that ... what the school did for him [her brother] was really the one teacher, or did you notice anything else? If they kinda kept an eye on him?

Family 7 Mother: I think they kept an eye on him. You know, I think that, 'cause I asked, if you see anything. And I think they're the kind of people, 'cause they were concerned. Uh, if they had noticed anything they, they would have called me. L1-5P38

## **Advocacy**

One of the unexpected findings in this study was that often parents were strong advocates for their children, the child with cancer and his/her sibling(s). Some parents expressed how difficult it was to deal with the schools. These parents had to be very proactive on behalf of their children. Some of these parents contacted the school right away to let the school personnel know what was going on and/ or to receive information about the steps for school re-entry. Some parents did not think the schools were honoring the 504 Plans when their children returned to school. Others were annoyed by the lack of communication from school personnel. The eight parents, who were advocates, had varying results. Two of the parents had very positive results. They were in the highest income bracket (see Table I, Parent Demographics, Appendix D). They also were very calm, but insistent when interacting with school personnel. The other six were in varying income brackets from highest to lowest incomes as shown on the Parent Demographic table. Socioeconomics, ethnicity, and gender did not influence the outcome of parent-school interaction in this study. Parents, who were very strong advocates, insisted that the school make positive adjustments for their children. However, one parent was so frustrated with the school, she started a lawsuit against the school. The principal would

not let the child come to school because she did not want the liability if the child caught a cold or the flu from other children. Two parents ended up going to the district offices because they could not get attention from the school administration. Two parents called a meeting with their children's teachers before they went back to school. The teachers did not follow through with what they agreed to do. One parent was Caucasian and in the highest income category. The other parent was African-American, in a predominately African-American school district, and of median income. In another scenario, a parent met with the sibling's high school teacher because the teacher was very insulting to her daughter. The teacher would not change her treatment of the sibling, so her daughter, a normally A student, had to take internet classes at home. Two parents researched information they needed before discussing what their children would need from the schools. One was successful and one was not. In the wake of their lack of success, parents were very demoralized and angry. One issue was that the parents wanted their children to go to school when they felt up to it. The parents' impressions were that the schools only cared about getting or losing money if the child was both home-schooled and attended school. One of these parents went to the school and met with the teachers, the counselor, and the vice-principal. Even with that, the attendance office threatened to have the child expelled because he missed so much school! Another problem was that work packets were not made available for the student by the teachers. The sister who had the responsibility of caring for her brother was constantly rebuffed by the school administration.

Family 3 Father:[successful advocacy] I've seen whenever something happen, because she deteriorates and can't go to class. I will always go back and tell the school to negotiate work for her.

Interviewer: So you would go if she wasn't.

Family 3 Father: I would.

Interviewer: So you were there a lot.

Family 3 Father: Oh, yeah. I'm very proactive as you mention, very proactive.

Interviewer: That is a lot of work for a parent, I think. And I think when you're thinking about everything else and your family, it's a lot to have to do.

Family 3 Father: Yes, right...

Interviewer: I don't think they get -

Family 3 Father: Uh-huh.

Interviewer: How hard and how much energy it takes to do one more thing. 'Cause that takes a lot of energy, what you did.

Family 3 Father: Yeah, it's a full time job.

Interviewer: It is a full time job. I know. That's the whole point.

Family 3 Father: Yeah, and most people need it, you mention that school may need to open the door. I don't know. But now you mention it, I don't even know, I didn't even know what right I had. I researched I could access. I didn't even know. So I would go back and request or find out something because only because I think my daughter need it. At that point, I don't know, what the heck, if resources I can grab to help her. I don't know. I will find out what resources they have. L6-23P17; L1-5P18;

Interviewer: Now, which personnel gave you the least support?  
Family 15 Mother: Everybody else. [other than the special education teacher]  
Interviewer: Okay.  
Family 15 Father: Uh-huh.  
Family 15 Mother: You don't hear from any of those other teachers unless there's an issue.  
Interviewer: What does the school consider an issue?  
Family 15 Mother: Not turning in homework.  
Family 15 Father: Right. Attendance.  
Family 15 Mother: Lack of attendance, maybe being tardy, things like that. They don't even ask - and, oh, don't miss school. Don't miss school. Because they didn't even realize, oh, yeah, he has cancer. Oh, okay. Now, we know. We've told everyone there for the last three years he has had cancer. Why do we need to do this every single year?  
Interviewer: How have the rest of the teachers responded?  
Family 15 Mother: When we tell them, they're very cordial. They're very responsive - oh, we understand perfectly, tell us what we can do. Ya-di, ya-di, ya. And that's been about it. That's usually as far as it goes. We've told the vice principal because each - the juniors, the seniors, the sophomores, the freshmen, everybody has their own vice principal. So we told the vice principal for the 11th, 12th grade - they all know. They don't know when it comes time to talk about his attendance or his grades, they all seem to forget.  
Interviewer: What have you asked them to do? Have you asked them to leave assignments for you or -  
Family 15 Father: When he was being home schooled, the school assistant told me, I called [the] Public School District office- they had told me there's a plan in place where he could be home schooled as well as go to school. So on days when he's feeling good, he could go to school.  
Interviewer: Right  
Family 15 Father: Uh-huh and when he's not feeling well, the teachers can provide the school work to him. And the home school teacher can help him because he'll be home schooled. So when he was going through his chemo and we were trying to keep him in school so we could keep everything kind of normal, I called them up and I said I wanted to get this. It's important, I want this to happen now. And they told me, "We never told you we could do that." I said, "Excuse me?" And they said, "We never told you we could do that." They said, "He's either going to have to come to school or he's going to have to be home schooled. But the teachers just don't have the resources in order to help you." I said, "Excuse me? I was told by so and so - etc. that this could happen and also this could and now you're telling me no?" And they said, "Well, we have never told you yes." And, I said, "Somebody's lying." I mean, I was indignant. L1-24P30; L1-16P31

## Discussion

The parents in this study had a variety of responses to their interactions with the schools. They were faced with a multitude of school-related issues which added to their stress. Even the parents with the greatest amounts of cooperation still had to call, arrange meetings about their concerns for their child, and ask the school to watch for behavior in siblings. Some parents did not even know what they could ask for because they were not informed of their children's rights. Parents had to manage both their family microsystem and two other systems, the medical and school communities. These relationships evolved and changed over time. Factor cC is applicable because this was the time when parents' perceptions of their efforts interacting with different systems was assessed

It was clear, that in many instances neither the school system, nor the hospital, met the criteria for each of the three phases of school re-entry (Power et al, 2003; Madan-Swain et al., 1999). In these cases, the schools did not initiate meetings with the parents to find out how the family was coping nor to effectively plan re-entry. The parents did contact the schools, but it was another responsibility on top of all their other demands. Optimally, it would have been ideal if all the parents had to do was contact the school about their child's cancer and have the school do the rest of the work. It would have been better if the hospital had contacted the school for the parents. Unfortunately, when hospitals were in touch with schools, there often was no specified point person within the administration to contact. Many children's hospitals now have liaison personnel to contact the schools. For the families in this study, this contact was not consistent.

As these parents told their stories, it became clear that they wanted empathy and compassion from the schools. It was clear that they needed the schools to listen to them, to validate their feelings, and to help their children. In eight instances, the parents were satisfied with the support from the schools. The family with the child with Down Syndrome was very happy with their son's teacher and aide. Another family also felt supported by the special education teacher. However, both felt the administrations of the schools were not as supportive. One did not believe the administration knew their child was ill. A few of the parents, such as the mother of F11, did not want to share their child's diagnosis with the community because they deemed it private information. Yet, when these parents did share their child's illness with the school, they expected support from adults outside of the family system. A parent who will only share their child's illness with one outside system, the school, is handing educators a precious gift of trust—trust that they will honor this confidence and help their child. The issue of trust and positive relationships is the message of the Poplin and Weere (1990) study. The importance of effective relationships and caring between the schools and parents was presented in a review of the work of Bronfenbrenner (1988), Sockett (1993), and Noddings(1992).

In 1988, Bronfenbrenner wrote an article emphasizing the need for strengthening family systems and for society to show more caring for its children. The article's main concern was for developmental scientists to find interventions to increase caring for America's children through the family. Bronfenbrenner stated that the development and survival of children depends upon the care and close association in activity with older members of our species. There should be time for parents, along with other adults in the child's environment, either within or outside the home, to show caring for the child. Bronfenbrenner focused on the workplace, but one can extrapolate that as the founder of



Head Start, he would also consider the school an equally important environment outside the home to show support for both the child and the parent.

This stance is supported by Sockett's (1993) belief in moral pedagogy. Sockett's definition of moral pedagogy includes 3 tenets: character, intellect, and caring. An important message is that, morally, the teacher should not have one set values for the home with different values for his/her role at school. The ideal of having moral character allows teachers to practice compassion and caring for parents and children. Parents stated that those teachers, who had a family member with cancer, understood the demands on the family and showed compassion to them. The traits of character encompass self-knowledge, integrity, courage, temperance, and justice. The dispositions of intellect include an ethic of rules, wisdom, fairness, impartiality and open-mindedness. School personnel can implement this ethic of rules, wisdom, and fairness within Kohlberg's (1981) highest level of moral development, the post conventional. This level of morality includes a social contract and the principle of conscience. In terms of parent-school interaction, school personnel should realize that a social contract, the one with the parents and their children, should take precedence over the school's impersonal mandates. A principle of conscience should be more important than dollars and cents. Lastly, the disposition of care includes a creation of trust from reciprocal relatedness.

Noddings (1992) equates caring with developing empathy, that it is as important in high school for teachers to address the emotional as well as academic needs of their students. She asserts that adolescents, in particular, feel uncared for in schools because their most pressing questions to do not get addressed such as "Who am I?", "What kind of person will I be?", "Where do I fit in?" and "How do others see me?". In addition, Sockett (1993) states that by high school the connection between educators, the student, and the family has dissipated . Some teachers do not even recognize their students when they see them in a context outside of their classrooms (Noddings,1992). An additive factor to this is that by necessity there is unequal power between the student and teacher. Though the relationship has to be this way, teachers can still model caring, allowing students to be the cared-for. To extend an attitude of caring, teachers must feel motivated to consider their students' thoughts and feelings. The relationship between teacher and student will maintain and develop continuity over time. Noddings is in sync with Bronfenbrenner (1994) and McCubbin and Patterson (1983) whose models emphasize that relationships develop over time. Parents said that their children were often not treated with understanding or respect. One of the teachers did not believe a child had cancer. This was probably due to the lack of intra- school communication. Others did not prepare packets or even recognize the student when he/she returned to school. Caring teachers responded to their students' needs. It made the adolescents in this study feel like they had a safe haven. In this study, many parents felt they had an unequal relationship with the school.

Noddings (1992) also feels that caring involves the physical self. Not only should we care for our bodies, but we need to extend caring to those with disabilities. Noddings would agree that this caring extends to children with cancer and their families. She also states that a component of caring is dialogue. School personnel must listen carefully to what a parent is saying in order to answer in a way that communicates caring. Where schools communicated with support, parents felt an enormous amount of relief.

Affirming Noddings' (1992) beliefs about the importance of a caring dialogue,

parents' perceptions of the school's response was that communication was a key factor. One example of poor communication was exemplified by the incident described by the parents of Family 15 in the section on advocacy. Communication was tangled, with everyone giving these parents different information. Walker and Singer (1993) and Slater, Martinez, and Habersang (1989) recognize the importance of positive school-parent dialogues when a parent has a child with a chronic illness. The key to a positive relationship is collaboration. The first step is the recognition that families are in a state of chronic and acute stress, that they feel isolated, and experience reduced autonomy (Slater, et al, 1989). The parents in this study mentioned how tired they were from increase of stressors that made coping with their child's illness so draining. They felt alone and were at the mercy of the school. These overwhelmed parents may have often come across as abrupt and demanding. It was the school's responsibility to understand that this is a reaction to the stress so that school personnel can adjust their communication skills to one of caring. Teachers may need training in listening skills which include signaling openness, reflecting messages, paraphrasing, summarizing, and questioning (Walker and Singer, 1993). Body language or pragmatics can distance a parent. For example, a lack of eye contact, facial expressions, and a body stance, like folded arms across the chest, can convey a lack of interest. Some of the parents in this study felt they were at cross purposes with school personnel rather than having a meeting where the goal was to problem-solve. In this study, it was apparent that school personnel did not have clarity about their role according to state and federal law and did not seem to have the time or knowledge to implement a process for providing services (Walker and Singer, 1993). The uncertainty of school policy was upsetting for these parents.

According to the results of the teacher and principal surveys, the teachers given the survey saw themselves as effective when working with a child with cancer. This is congruent with the fact that these were the teachers the parents chose to do the survey. Parents thought these teachers were extremely supportive of their children. These teachers often wrote additional comments about their roles, usually positive, showing caring about the child and the family. Principals also self-selected to fill-out the surveys. Even though parents gave their names and contact information to the researcher, the principals were under no obligation to participate. Principals saw themselves as offering training, and help to general education teachers and accommodations to the child with cancer. Teacher and parent data showed that they had different perceptions about what was offered. From the survey information, it is clear that the principals and teachers wanted to be supportive. Neither one of each category would have taken the time to do the survey if they did not care.

Effectiveness was correlated with communication. When principals, teachers, and parents were in constant communication amongst themselves and with each other, the results were very positive. Unfortunately, when there was a lack of support, caregivers perceived the school as a negative resource. A lack of support symbolizes a frayed connection between the systems of the family and the school. The trust between the parent and the school has been broken.

Communication is greatly influenced by the culture of the family and the school systems. Cultural differences can affect communication because terminology of the two cultures, the family and the school, can have different meanings for each group. Furthermore, it is essential that school personnel recognize their own biases, attitudes,

and beliefs which have been ingrained from their own personal cultural experiences (Walker and Singer, 1993). These biases and attitudes of school personnel influence communication, just as parental communication is molded by parents' experiences.

Culture is a social construction. McLaren (1989) asserts that the term "culture" signifies particular ways in which a social group lives and makes sense of its circumstances and conditions of life. Gollnick and Chinn (1994) assert that one's culture includes a set of practices, beliefs and values which help make sense of the world. Regardless of socioeconomics, gender, or ethnicity, the parents in this study are now members of another subculture, that which has a child with cancer. Childhood cancer is a social strata equalizer. In this study, parents of higher socioeconomics did not have the same power as the school system, which represents the dominant culture or macrosystem. The social practices of this culture affirm the values, interests and concerns of the social class in control of wealth and power (McLaren, 1989). These parents were not used to working with the school from a position of need. Also, many of these parents were not conversant in their legal rights. Therefore, they have reduced social capital. The language, customs, and values that now make up the parents' small subgroup can be at odds with that of the school, which is not used to working with this particular population. Both the dominant culture of the school and the subculture of the parents are challenged to find a working social relationship.

A part of communicating is advocacy. Quite a few parents worked hard to advocate for their children. They had confidence in their abilities to handle issues on their own. They displayed self-efficacy (Bandura, 1989). These parents, both male and female, researched what accommodations their children were entitled to receive. Trainor (2010) conducted research about parent advocacy and special education. She found that knowledge of cultural and social capital was the one factor that accounted for successful advocacy. Cultural capital is having knowledge of the system and the law. Social capital is the ability to communicate effectively. In an email from a parent to the researcher, a mother stated that the family relationship with the school was very good. She went on to say:

We didn't really have any problems and teachers were always responsive to any questions. Relationships are a two-way street, though, because parents need to show up for open house and know what the teacher expects of the kids in class. We paid attention and, if the kids were having a problem, we asked advice from the teacher (August 4, 2010).

This mother had social capital. This capital gave her the confidence to work productively with the school. She understood that relationships that are bi-directional are be most effective. If her children had a problem, she went directly to the teacher.

Trainor 's (2010) study examined those who do not have cultural or social capital such as non-English speaking parents or new immigrants. The current study did not look at that population. Trainor found that parents who were less demanding and used a more respectful tone were able to receive more services. That was also the case in this study. While Trainor found socioeconomics and ethnicity a factor, this study did not.

Similar findings to this study were found in the studies by Christensen and Sheridan (2001) where there were no significant differences between parents according to socioeconomics and ethnicity nor types of service provided by special education or general education. However, in this study, parents found the most empathetic teacher to

be the special education teacher. Parents in the Christensen and Sheridan study found, as did this researcher, that there was low trust in high school personnel. This is consistent with Sockett (1993) who also stated that the higher one goes in the school system, the less the sense of *in loco parentis* is present.

The siblings of the child with cancer represent another part of this subculture of illness. Unfortunately, there is very little research on how siblings react when a brother or sister has a chronic illness (Thompson and Gustavson, 1999). They did say that the closer the age spacing the more risk for adjustment problems. This was evident in one family where the older brother had great difficulty in school and was acting out. Thompson and Gustavson (1999) said that mothers and teachers also reported that older sisters and younger brothers have higher rates of adjustment issues. This was true in this study for quite a few families. In one family, the older sister, a straight A student, clashed with one of her teachers to such an extent that it ruined her attitude toward school. She ended up being homeschooled. In another case, the child's younger brother had to be schooled at the hospital, making friends with patients who were his age. He had experienced the deaths of a few of these friends. This boy had a difficult time readjusting to school. As one mother said, siblings are the other victims of this disease.

In summary, from the parents' perspectives, some schools did not know how to relate to and care for families with children with cancer. The perceptions of teachers and principals were that they did a good job interacting with these families. Yet, many schools have not had experience having a child with cancer. Most parents took the time to interact with the school personnel at some point. In this study, socioeconomic, ethnicity and gender were not correlated with a successful relationship with the schools. Parents at the same income level, with differing ethnicities, received the same results. Fathers who were actively involved had the same success rate in dealing with the schools as did the mothers. Schools were most cooperative with parents who were calm and soft spoken compared to those who were demanding and expressed frustration. It seems that best results were achieved when the child was in special education, the child was an outstanding student, or a teacher in the school has had a family member with cancer. However, even the Caucasian mother in the highest income level, who had good results when advocating, did not want the researcher to survey the principal and a teacher. She said that they were too busy writing college recommendations, but this was in March, a time when work on college recommendations is minimal. The researcher sensed that she "did not want to bother them" because she feared that the school would not keep an eye on her daughter and her daughter's sibling. Also, very few parents knew what legal accommodations were available for their child although most received a 504 Plan. In most cases, the hospital staff neither communicated with the school regarding how the cancer could affect learning, how to obtain a home teacher, nor offer to go to the school to educate school personnel and/or students about what having cancer meant in terms of social emotional re-entry. Often, communication within the school was poor. Some personnel knew about the child's condition, while others did not. Ultimately, successful communication was achieved, when the school, a representative of the dominant culture, was able to care for members of the subordinate culture, the families with a child with cancer.

It was clear that often school response added to the parents' stress. Even when the school was helpful, the parents had to reach out to the school. Their ability to research

information and advocate for their children was a resource. Caring school personnel were a resource. Factor cC, in the Double ABCX model, refers to the original stressor, cancer, and how the parents meet and manage demands and challenges. Those who were new to working with schools developed more assurance and knowledge over time. They usually found someone in the school who would support them. Factor xX is the families' overall adaption to the cancer and the schools. These parents adapted to having a child with cancer and managing interactions with the school. As in Bronfenbrenner's model (1994), the factors of interconnection of systems, culture, and communication determined the success of parent-school relationships. Both models recognize that the management of events, stressors and resources develops over time. With the fresh eyes of a subordinate culture, that which has a child with cancer, parents experienced their social interaction with the schools in a new way, often, as that of an outsider.

## Chapter 8

### Results IV: Children's Perceptions of the Schools

#### Not Being Able to Go to School

Teenagers want to have what Sourkes (1995) says is normality in their lives. The knowledge that they cannot go to school is a disappointment. The adolescents think of school as a resource. All of the students interviewed missed school for various reasons including worries about falling behind or getting back into sports. The adolescents were forced to depend upon their parents. There was no room for much autonomy.

Interviewer: Right. Right. I think that, well so what was the first thing that came to mind when you realized what was going on?

Family 7 Female Child: School pretty much.

Interviewer: Oh, interesting.

Family 7 Female: I go to a really, really intensive high school. Like we're rated, I think 36th in the nation recently, by like news reports. So, really competitive. And I realized I'd missed like two or three months of school. I was thinking, there's no way that I'm going to be able to go back. It would, it would be impossible for me to make up three months of work.

Interviewer: Oh, gosh. How frustrating.

Family 7 Female: Yeah. And there's all those like medications I was on. I was still feeling like really nauseated. I still had all these IVs. I like, we were starting all those other side effects. I was barfing all the time. I'm like, I'm just not going to be able, I'm not going to be able to keep up with like the coursework.

Interviewer: Right.

Family 7 Female: So like my immediate concern was, oh God. How am I going to be able to like keep up with the school. L1-17P45

Interviewer: How did you feel when you couldn't go to school?

Family 8 Male Child: It took my heart away. L22-23P1

#### Returning to School or Home Schooling

Students wanted to go to school, but were concerned how it would go. Would their peers treat them the same? Would teachers understand what changes they would now need to facilitate their learning? Some students were being homeschooled so they had a different point of view. It is important to remember that many of these students were still receiving some kind of treatment or, at the very least, having check-ups.

Family 3 Female: So I couldn't understand what was going on. But, um, once I got back to school, it was very overwhelming because I had to all of a sudden get back to work and finals and, and I get to see all my friends again and they all changed since middle school. 'Cause they all grew up and became very different people. So I was still pretty alone, I guess. 'Cause I didn't know who they were much anymore. L20-24P

Interviewer: Well I meant with the home teacher.

Family 6 Male Child: Yeah, yeah.

Interviewer: Are you looking forward to that?

Family 6 Male Child: Yeah, 'cause in the afternoon I'm gonna be all busy

and all that and then in the morning that's the only time I'll have, so then, yeah, I'm kinda excited.

Interviewer: That's good.

Family 6 Male: Trying to get my education back and all that. L1-7P50

### **Peers, Cancer and Returning to School**

The overall response to going back school and seeing friends was surprising to the researcher knowing how enmeshed adolescents are with their peers. Studies have shown that support from classmates is a resource for returning students (Thompson and Gustafson, 1996). In this study, it was clear that close friends served as protective factors, acting as buffers between the returning students and their other classmates. Once the students at school knew the truth about the illness, they did not overemphasize it. The support of their close friends made it easier for these adolescents to enter the system again.

Usually, teens care what their peers think, and they want to belong (Liddle & Schwartz, 2002; Sylwester, 2007). Most of these children did not care what people thought. This was especially unusual for female adolescents because the stereotype is that girls want to fit in by dressing and wearing their hair like their peers. Actually, in this study, the males were more self-conscious than the females. Most did not want to go back to school until their hair had grown back or they could be an athlete again. This finding is supported by the study done by Offer, Ostrov, and Howard (1984). Males were more sensitive to the impairments in their bodies than the females. Upon returning to school, one boy was called a skinhead, and stated, "I just ignored it." The same young man is quoted below (F16). He did not want his peers to treat him differently, yet he was glad to be back at school

Interviewer: Okay and, um, so, how do you feel about that?

Family 11 Male: Just the fact that is, like so I can like, you know, get my momentum back and then start growing all my hair back and then get to pull off the wig – um,

Interviewer: Yeah, so you want to go back to school – you're waiting till your hair has grown back.

Family 11 Male: Yeah. L3-8P47

Family 7 Female: So I looked fine for the most part except that my growing my hair was back. It was about an inch long and I'm like, I looked like I'd lost some weight. But other than that, I was pretty much healthy and since everybody, most everybody knew what I had gone through, I didn't get a whole lot of like, "Why's your hair so weird?" and things like that. It was just kinda said, but "Okay, she's coming back." Like, give her a break. L6-11P49

Interviewer: All right, um, so you didn't want the whole school to know and, or other people and why was that?

Family 16 Male: 'Cause, um, I didn't really want them to, to know my business. Uh, 'cause then they would just treat me differently. L9-12P4

## **Hospital and School**

The interaction of the hospital and the school can be a resource. Only four students knew anything about how the hospital and school communicated with each other. One agreed with her mother that there was no dialogue. Another thought they did not help, while another student's family was told the school did not have time to work with the hospital. One of the girls thought the hospital did a great job arranging her placement tests for college. The students received help depending upon if the hospital and school worked together.

Family 6 Male: They put me all zeros and all that. 'Cause I was, the lady at the hospital's supposed to be in contact with them.

Interviewer: And she didn't do it?

Family 6 Male: She didn't do it.

Interviewer: So, when you got all zeros, did you have to go back to court again?

Family 6 Male: No, uh-uh. We just got that straightened out. My mom talked to my social worker – and then -

Interviewer: At the hospital?

Family 6 Male: Yeah, at the hospital and then, uh, because I guess she didn't fill out the application. L9-14P49

Family 7 Female: But I was taking my standardized tests then. I took my SAT, my SAT Subjects, my AP class. That was really intensive but I did well and I got them over with and that was my feeling, it's amazing that the hospital school was able to arrange that for me. Because the only ways I was able to take them was because I could take them through the hospital school. L13-17P54

## **Teachers' Knowledge of Cancer**

The teacher's knowledge of cancer is an integral part of the student's adjustment. This can be a stressor or a resource. One factor is that often teachers either do not have information or they receive misinformation about cancer (Sexson and Dingle, 2001). The results in this study suggest that when teachers understand the effects of the cancer physiologically and academically, they can better help the student. If they do not, the consequences can be disastrous for the student. Anecdotally, one boy, 14, had been treated for cancer the year before his freshman year of high school. When the parent told the counselor, the counselor said she would notify the teachers. The parent also asked that his teachers notify the counselor if he exhibited any unusual behaviors. Unfortunately, the physical education teacher did not understand the psychology of cancer survivors because no one had educated him. This is understandable and is supported by the teacher survey in this study where all but one of the teachers indicated that they did not have any in-service training about childhood cancer. Since cancer is considered a high-incidence chronic illness, it is particularly important that teachers have an opportunity to acquire knowledge about this illness. In the instance of the high school student above, there was obviously no communication between the counselor and the physical education teacher. When the young man was reluctant and unable to dress for gym class after being on the track team, the teacher gave the student an F. If there had been communication between the counselor and the physical education teacher, the teacher would have known that



when a student who is off treatment feels fatigued, he is often afraid that he is getting ill again. An adolescent would most likely not verbalize this to the teacher. In this study, the female below felt her teachers overall did not understand her situation. They babied her, which she knew they meant as a kindness. In our interview, her tone suggested that they just did not understand her situation. According to Kline and Rubel (2001), teachers may become overprotective. This was the circumstance in her case.

Family 3 Female: Um, they treated me like I was a child, or like 'cause they didn't know how to treat me, because they didn't know about my sickness. So I guess in a way they had patronizing me, although I don't blame them. But, um, I guess there was a feeling like, I mean they were really nice about it and understanding. And if I got sick they would give me extra time to catch up with my work and all that. L17-21P7

Family 11 Male: The teachers knew what it meant. Some teachers didn't really get it overall. L23P21

Yes, Ms. L, the assistant principal had talked to me. She had had to deal with the side effects and understood what was going on. I didn't meet with her that often. L1-2P22

She did sometimes notice I was tired and that it was affecting me in some way by the way I was walking and learning. L7-8P22

### **Learning Issues**

Chemotherapy can affect brain function, with some treatment protocols having more late effects than others. For example, children treated for a brain tumor with cranial irradiation and those treated with spinal chemotherapy tend to have more serious side effects (Sexson and Dingle, 2001). They can develop non-verbal learning disabilities. Most children experienced dysfunction during treatment, but regained their learning skills within a year after diagnosis. These learning issues included problems with inattention, problem-solving, and math. Comprehension was a problem along with short-term memory loss. These were the learning issues in this study. Physical side effects included lack of energy which also affected the children's ability to focus and to take in information.

Interviewer: Was it hard to pay attention?

Family 16 Male: Yeah.

Interviewer: Do you think it just was the treatment or do you think that that kind of changed in you and you couldn't pay attention.

Family 16 Male: Um, it was kind of the treatment 'cause I was tired all the time.

Interviewer: Right. Right. So after treatment you were more alert.

Family 16 Male Child: Yeah.

Interviewer: Could pay attention more?

Family 16 Mal: Uh-huh. L12-20P6

Interviewer: Okay. Did they modify your assignments so you could still learn but just have less to do?

Family 16 Male: Uh, no. They'd give me, like, the same assignments, but, like, they just didn't make me, like, do um as fast, like, 'cause everybody, like, I could turn um in, like, a little later and I would get, like, some I

would get in bulk because, like, sometimes I just wouldn't show up.  
Interviewer: Right, right. Yeah. Did they...grade you down if you turned it in late?  
Family 16 Male: No.  
Interviewer: Oh, that was nice.  
Family 16 Male: Yeah. L14-23P3

Interviewer: Okay, all right. Well, and speaking of school – how has having cancer affected your school performance?  
Family 17 Female Child: Having cancer has made my school performance weaken, I think.  
Interviewer: Okay.  
Family 17 Female: My grades are the same but finding the answer to a problem or a question has become a whole lot harder than it was.  
L9-14P8

### **Support and Lack of Support**

Schools can serve as resources if personnel are supportive, but if not supportive, they are added stressors. Two tables were created to compare the children's perceptions of support and lack of support by school personnel to that of their parents' interviews and Likert scale ratings (See Appendix D). Overall, parents focused more on the administrators, the attendance office, and the nurse. The children focused more on the teachers and the school personnel with whom they had the most contact. Six of the responses were not applicable because either the mother was not interviewed or the child was not interviewed. Seven of the eleven children interviewed had concordance with their mothers in regard to at least one of the school personnel. In terms of least support by school personnel, both the children and their mothers were the same in only five instances. Six had no agreement and six were not applicable. This result could be explained by the fact that mothers were working with administrators, trying to improve the quality of their child's school experience. While eight of the fathers participated, two did not want their children interviewed. This lowered the possibility of having similar answers.

In terms of most support, there were 4 responses in agreement with fathers, two-thirds of the total father-child dyads. In one case, a stepfather was not interviewed, but his Likert ratings matched his stepson's answers. One father, divorced from his son's mother, had no contact with the school. The results illustrated that in most cases, the mother was the caregiver who had the most contact with the hospital and the school. The children's perceptions of the support they did or did not receive pinpoints whether the students felt the faculty acted in loco parentis. Their answers tell us if there was an atmosphere of caring.

**Support** There are three systems that work with the child with cancer. One is the family, one is the medical community, and one is the school. Students with cancer come to school with a recent history of family dynamics revolving around their illness, the hospital which is concerned with survival, and the school which represents a place of normality. Therefore, the school is a very important place for these children to be. If teachers and other school personnel showed caring in the form of understanding and

guidance, the child with cancer was able to regain a sense of self-efficacy and autonomy—the role of a teenager in child development.

Family 1 Female: Um, we had homeroom in 7th grade.

Interviewer: Right.

Family 1 Female: And we were doing a Pennies for Patients, it's like you bring pennies to raise money for the Leukemia Lymphoma Society.

Interviewer: Okay.

Family 1 Female: And, my homeroom teacher had me talk at homeroom.  
L7-12P12 A.

The homeroom teacher above showed understanding about this girl's illness, validated this student's experience, and made her feel important.

Family 11 Male: It was just, um, everybody would be helpful if I needed anything. If I needed to take a break. I'd go to the nurse's office. They'd let me relax a little bit and then I'd be sent back to class. Everybody was helpful. They tried, they tried to make everything like as normal as...L24P19; L1-3P20

Interviewer: And, so the teachers all knew. How did they know?

Family 11 Male: ... 'cause, uh, the faculty, like, well, like, the principal and all that knew and my counselors. And, uh, they would, they told my teachers so, like, which would make it easier on me.

L24P3; L1-3P4

**Lack of Support** If showing support left the student feeling cared for, the lack of support only added to feelings of isolation. When students lost faith in the adults who were charged with their care, they felt frustration. In one instance, a straight A student was given a C by a teacher in math. Her mother said that her daughter thought because the teacher was inexperienced he was not able to provide accommodations for her. In another case, the principal was in charge of making sure that a student's 504 Plan was implemented by the teachers. He failed to do that and the student had a difficult time with her school re-entry. Teachers had the power in the relationship with students. Therefore, when students returned to school, they were already on the weaker side of this dyad. So if there was a lack of support, the student's anxiety increased. The student had feelings of trepidation upon seeing his peers again, so the lack of support in school only added to the child's level of discomfort. Lack of support equaled an increase in stressors.

Family 3 Female: So I guess I had this one econ teacher who's 30, like 30-something. I guess he has a hard time trying to understand, like when I'm sick I need like extra time to, um, to work and stuff and I guess he just, he just treated me like, um, I should be more responsible or, um, I needed to get work done faster and, or else he's going to fail me, or - L2-10P8

Interviewer: Wow.

Family 3 Female: Or something like that and, and then, I tried to explaining to him that I had leukemia and I had, you know, the side effects and stuff like that. And, I guess he was pretty harsh. So I had to work my ass off for that class.

Family 9 Female: When I was in 10th grade, my English teacher, because I was so sick, ...And because I was absent I would say to my teacher, I'm

sick. I'm in the hospital,...read my 504 plan. She didn't care. So she would count me absent and because I was absent so many times in her class, she failed me. And so, I got... an incomplete... the second semester of my 10th grade. L20-24P14

### **Discussion**

The results are more cogent when analyzed within the theoretical frameworks, the Double ABCX and bioecological models. In addition, the work of other experts provides additional insight. Within the Double ABCX model, the factors leading to adaptation, Factor xX, fit the process of students returning to school and all that entails. Furthermore, this model looks at the passage of time along with the increasing load of stressors. Factor aA is the original stressor, the diagnosis of cancer, along with the interactive and additive strains of re-entering school. The first interactive and additive elements are to go to school while still maintaining a relationship with the hospital. Factor bB is important because it recognizes the resources or lack thereof made available to the students. Time is a factor because the length of treatment determined the amount of time that the child could not attend school. It also took time for the child to adjust to school. Factor cC examines how the adolescents perceived the impact of having cancer, while, at the same time, managing re-entering school. Furthermore, Factor cC looks at how these students meet these challenges. Students managed returning to school by getting support from close friends, their parents, and school personnel who knew of their illness, such as the nurse.

According to the bioecological model, it is important to have bidirectional relationships between systems, such as the hospital and the school. Ideally, the two systems interact to exchange information. The communication, the mesosystem, is between these systems, which are a part of the exosystem in this instance. Their communication does not include the child, but affects what happens for the child at this point. Overall, the students did not think the hospital worked with the school. This meant there was a lack of education about cancer for school personnel. Kline et al. (2001) states that initially education and medicine were intertwined as physicians considered the biology of the child, one microsystem, and education as a part of their domain. Now, the two professions are totally separate. Special education does use a medical model, but there is no law that delineates what the physician's place is within this aspect of education. There are schools in hospitals that often do get the homework from the child's school. However, there is no dialogue about how the treatment affects learning. There is a breakdown of interprofessional collaboration (Kline, et. al, 2001). Some schools had school nurses, but they worked in the capacity of caring for the students, giving them a place to rest and, at times, informing the parents how their children were doing. These nurses did not educate the staff about the effects of cancer. The nurses did, however, act as a resource for the students.

A factor that most likely influenced the child's return to school was probably the unrecognized emotion teachers felt when working with a child with a serious or chronic illness (Sexson and Dingle, 2001). Teachers are not educated about what to expect and have no support system within the school culture to express their feelings. In this study, some teachers were very difficult. Possibly, this was a reflection of their unease when working with these students. Questions about their roles may arise: Am I responsible for

this child's re-entry? Should I be calling her parents? Worry about the child's health could have caused some teachers to become overprotective.

Just as there was a lack of communication between the hospital and the school, there was a serious problem with disseminating information to the school staff. The culture of the secondary schools is one of disconnected pieces. Each subject has its own group of teachers. These groups are not often engaged with the administration. These teachers may have one hundred students or more in a day. In addition, it is very unusual for the principal to have an all staff meeting. Counselors are overwhelmed with their caseload of students. The school culture is fractured. Therefore, the teachers, in this study, might not have known if there is a 504 plan written for a child returning to school. If they were aware of the plan, they often may have found it inconvenient to implement because of all the other students in their classes. One of Sockett's (1993) assertions is that the higher the education, the less the caring there is for the students. In the case of the child with cancer returning to school, the principal or counselor did not consistently communicate with the staff, resulting in poor intrasystemic relations. In turn, this breakdown led to a less than positive transactional teacher-student relationship. The job of the student became one of advocating for oneself and/or doing the work at the same level as the class. Within the Double ABCX model, the student had to know what resources were available, Factor bB, and manage them accordingly, Factor cC.

When there was positive communication, and the teachers adhered to the 504 plan, the students were given the accommodations they needed. Three students felt they received support from the school as a whole. These students smiled when talking about their teachers. They had a strong feeling of being cared-for (Noddings, 1992). Sockett (1993) would be impressed that a middle school and three high schools treated these students *in loco parentis*, exemplifying moral pedagogy. Bronfenbrenner (1988) would also be pleased because these adults outside of the family system were taking responsibility for these children. The special education teachers were the ones who most often were credited with nurturing their students and being advocates at school. Some general education teachers were mentors, who inspired these students. Other personnel showed caring because of a personal connection. Someone close to them had cancer or had been very ill. These personnel developed trust which is so important in teacher-pupil relationships (Poplin and Weere, 1993; Watson, 2003).

However, none of the experts cited above would be pleased with how many teachers were listed as stressors in the students' lives. They did not send work home, give these students extra time, nor accommodate their learning issues. The principal, at one school, would not reprimand students when they betted on whether a girl would have a seizure on the night of her prom. Sockett (1993) would say there is a lack of moral pedagogy, specifically an ethic of intellect which fosters justice and consistency of rules.

The ethic of care emphasizes responsiveness in the context of trust. Three students felt they did not get any support from the faculty as a whole. In some cases, even the attendance office added to the stress. They followed the rules without being fair or caring.

Not being able to go to school was both a stressor and a resource. Some of the students who were homeschooled saw it as a resource. These teens could study when they felt well enough. This also gave them a reprieve from having "everyone know my business." They wanted the safety of their own family system. The boys, in particular,

wanted to stay within their social system, or, as one boy put it, “.my posse”. Some of the boys were self-conscious about their appearance, which was a stressor for them. It was interesting that the girls did not feel that way. They just wanted to go to school and did not care what their peers thought of their hair loss. This is the opposite of the triple bind which represents the expectations of females in our culture (Hinshaw, 2009). Girls are supposed to be pretty and sexy, caregivers, and accomplished professionals. The females, in this study, valued school and their friends, but were not concerned about their appearance. They had experienced having a life threatening illness, and were still being monitored by their doctors. As a result, these young women had matured and were managing their life situations as best as they could. This meant not worrying about their hair. Both the boys and the girls were using the skills, Factor cC model, to appraise their resources and manage their challenges.

Returning to school meant adapting to another system, with its own expectations, both academically and socially. When students re-entered school, they were leaving their family microsystems, and attempting autonomy for the first time since their diagnosis. Some of the students felt trepidation, while others were glad to be returning to school. Factor cC of the Double ABCX model applies here because the teens were trying to manage this new challenge. This was definitely a challenge because their first concern was how their peers would treat them. A group of peers walked up to one boy who had been out of school for awhile. They told him they thought he had died. Some of the girls had to make new friends because either their old group did not bother with them or the group had started using drugs. In addition, none of the teens wanted special treatment from their peers. They were acting like typical teenagers, not wanting to stick out. Of course, if their appearance was changed, they felt they had to manage that as well. All of the children, including the child with Asperger Syndrome, had good experiences socially once they adapted to changes in the school culture. The young man with Down Syndrome returned to his special education setting with no change in routine or friends.

It was clear that school re-entry in this study did not follow the prescribed model in the literature review (Madan-Swain et al., 1999; Power et al., 2003). According to bioecological model, these children were dealing with the biology of their bodies, while straddling three systems: the home, the hospital and the school. Often there was poor communication between systems so the student had a more difficult entry into school. The Double ABCX model looked at the multitude of stressors and how the student perceived and managed the challenges of school. The school was a resource for some students, providing caring. For others, the lack of support added to the growing mound of stressors. Ultimately, in terms of Factor x X, all of the adolescents adapted to the stressors, resources, and systems over time. If teens could fight cancer, they could adapt to school and retain some semblance of normality.

## Chapter 9 Discussion

The purpose of this research was to explore how schools respond to families who have a child with cancer. This study used McCubbin and Patterson's (1983) Double ABCX model and Bronfenbrenner's (1994) bioecological model to determine whether parents of children with cancer perceived schools as a stressor or resource. This study also compared these parents' experiences to the model of school re-entry. Kazak, Christakis, Akderfer, and Coiro (1994) state "it is becoming increasingly important to understand the mechanisms that either protect or endanger the growing numbers of pediatric cancer survivors. Doing so requires focusing not only on the individual survivors, but also on the systems (families, schools, hospitals, and clinics) with which these children interact (9)."

The following objectives were investigated to see how pilot study findings compared to this study:

1. Describe and compare the impact of cancer on parents.
2. Describe if and how schools support parents in terms of moral pedagogy.
3. Describe if and how schools support the children with cancer in terms of moral pedagogy.
4. Explore whether ethnicity, gender, family constellation, and socioeconomic status can result in differences in how schools treat parents of children with cancer.
5. Discover what factors determine parental advocacy for services for their children with cancer.
6. Make recommendations, if indicated, for changes in educational policy regarding the needs of families who have children with cancer.

Within these models, other important questions motivated this study: 1) How do parents and the child with cancer cope when facing school re-entry? 2) What do parents and the child with cancer want from the school system in the way of support? 3) What are parents' perceptions of school support? 4) How do schools support the entire family? In addition, the themes found in the pilot study were compared to findings in this research project. These themes in the pilot study included:

- Diagnosis was a shock and life-changing.
- Children's reactions to their cancer were related to their parents' reactions and to their developmental level as well.
- Children's peer relationships did not tend to be affected by the visibility of treatment.
- Three of the four families saw long-term affects in their children ranging from health, fertility, and/or academic/vocational issues.
- Two of the four mothers developed cancer later in life and related it to the stress of their children having cancer.
- All parents reported closer marriages, even if there were problems prior to the diagnosis.
- Gender made a difference in the style of parental coping.
- Nuclear families reported that they drew together and became closer.
- Schools did not facilitate re-entry according to the phases described in the literature.

## **Theoretical Framework**

This study applied McCubbin and Patterson's (1983) Double ABCXC model and Bronfenbrenner's bioecological model to provide a framework within which all the factors stated above could be examined. The Double ABCX model looked at a buildup of stressors as they related to the initial stressor, which, in this study, is the diagnosis of childhood cancer. The bioecological model assessed the interaction of systems, both internal and external to the families. Both models purport that crises evolve over time. In addition to these models, the interplay between parents, children and the schools was appraised in terms of moral pedagogy (Sockett, 1993) and caring (Noddings, 1992).

These models were applied in order to analyze the responses of parents, children and educators as shown in the research instruments. These measures included interviews with the parents and children, a demographic survey for each of the parents/caregivers, and surveys for the school principal and one educator selected by the parents.

## **The Importance of Stories**

Researchers have written about the importance of stories in research (Ferguson and Ferguson, 1995; Powers, 1993). It was therapeutic for families to tell their stories. As parents told their stories, with the guidance of the interviewer, their body language added to their narrative. They leaned toward the interviewer with intent looks on their faces. This intensity increased as they told of the difficulties of their lives as events had unfolded. With a positive narrative, the parents' bodies visibly relaxed, and some had half smiles on their faces. Usually parents responded with more stories when the researcher asked them if there was anything they would like to add. Interestingly, after the interview seemed over, parents thought of more to say, so the tape recorder was turned on again. This did not happen as often when the children were interviewed.

Examining perception is key to qualitative research analysis. Establishing a relationship with the interviewee is essential to a productive interview. Parents physically relaxed knowing that the researcher's son had cancer as an adolescent. I wanted the parents to feel as comfortable as possible because I was asking them to bare their souls and relive difficult, painful times.

## **Burdens of Parents**

The agreements of themes with those of the pilot study were as follows:

- All parents were shocked and felt their lives changed forever with the diagnosis.
- Many parents did find that their relationships became stronger.

There were different findings from the pilot study:

- There were two divorces as a result of this diagnosis. In one case, the marriage was in trouble already. Their child's illness was one problem too much for the marriage to sustain itself. Another marriage, which had been stable, fell apart under the weight of the illness. One parent said that it strained their relationship. It also adversely affected the tenuous relationships between divorced couples.
- Many nuclear families had to reconfigure their family microsystems. For some families, this meant leaving a teenage daughter in charge while her stepsister was receiving treatment. Siblings, in general, had difficulty adapting during treatment. In fact, years after the crisis, siblings have continued to express sadness and resentment about the overall lack of



support (Kaffenberger, 2006). Anecdotally, the researcher has spoken to parents of siblings of long-term survivors. These siblings experienced strong feelings of resentment as much as 20 years after the diagnosis. This was one more residual stressor with which the parents had to cope.

- Gender did not make a difference in parental coping styles. Historically, mothers have been the primary caretaker for the child with cancer, while the fathers coped by working and helping with the child's siblings. It surprised the researcher that often fathers were either the main caretaker for the child with cancer or, if not, would help out by bringing the child to the hospital for treatment. These fathers were very open about their feelings. While many fathers worked and took care of the siblings, they were also very involved with discussions with all their children about emotional issues.
- Because treatment was still on-going or had ended in the recent past, it was too early to tell whether parents would see long-term affects in their children relating to health and/or academic/vocational issues. Fertility issues were not important to these parents. They just wanted their children to stay well.
- Because of the short time period involved, it is too soon to tell if the effects of the strain impacted mothers' health. One parent was diagnosed with a brain tumor, but it was growing before the diagnosis.

There were other findings about the family microsystem in this study. The history of the families underscored the difficulty of their lives. Quite a few of the parents had experienced tragedy in their families. Families had children that had died or had to be institutionalized. In one family, the boy with cancer also had Down Syndrome. During the boy's treatment, his mother was diagnosed with a brain tumor and his sister was operated on because of severe cataracts. Another father had a sister who died of cancer at a young age. Then, he had to leave his native country because he had a son with autism. This foreign country shunned anyone with a disability. Another family lost everything because of the costs. Also, unlike the pilot study, there was an array of family configurations. There were single mothers, an older sister in charge of her brother's health care, and those with second marriages. Every one of the families had some type of monetary problems, even those with higher socioeconomic status. This was because of medical costs.

From the parents' answers and demeanors, it was clear they carried the burden of emotions typical of symptoms of post-traumatic stress disorder (Baraket, et al. 200; Kazak et al., 2001). This is concordant with the parents in the pilot study. Even though their children had been diagnosed between ten and twenty years ago, those parents were still affected by the experience of having a child with cancer. As with the parents in the pilot study, the parents in this study lived with the fear that the cancer would return, that the sword of Damocles would make the cut that would crush their hopes. The parents were constantly vigilant about their children's health. They were also worried about late effects from the treatment. These late effects manifest themselves as learning issues most often. Also, these parents were worried about the future effects of the chemotherapy.

## **Trauma for Teenagers**

Just like their parents, the students expressed initial fear, anger, and denial. As time passed, they were determined to be positive. In the pilot study, parents noted that their children had the same reactions.

## **Living with Cancer**

As in the pilot study, it was difficult to be ill and be a teenager. These adolescents missed their friends and activities. Some felt isolated from their peers. Living with the physical and mental side effects was frustrating. Side effects of the treatment included exhaustion, nausea, and the inability to think clearly. In some cases, the children were too tired to interact with their friends when they visited. One girl was so “sick and tired of being sick” that she attempted suicide.

It was found that most of the teenagers did not feel self-conscious about hair loss. This attitude is inconsistent with most of the literature about the negative impact of hair loss on self-esteem (Copeland, 1983). In this study, the teens generally thought that they had gone through so much, that hair loss was a small price to pay for staying alive. One young man was called a skinhead at school and was able to ignore it. This mindset was especially unexpected for the girls.

Some teens wanted a chance to experiment with smoking and other typical teenage activities, but did not truly rebel for various reasons. This included a fear of using recreational drugs with their treatment, being confined to home or the hospital, and just not feeling well. A conclusion from these findings is that, in their own way, these adolescents established their identity, not through external standards, but rather through their internal beliefs. They wanted to feel well and stay well.

**Peers** All of the teenagers with cancer had some very close friends who visited them at both the hospital and their homes. However, many of the children changed peer groups, having one set of friends pre-diagnosis and another set of friends post-treatment. One of the reasons they changed friends was because they themselves had a different set of values as a result of having cancer. The girls, in particular, thought that many of their former friends were shallow. Another finding was that most peers did not understand what it meant to have cancer. In one instance, a girl’s friend said “the cancer was talking” whenever they had a disagreement. Her friend saw the cancer and not the girl. On a television series, *Grey’s Anatomy*, a teenage girl did not want to tell the doctors that she felt her cancer had returned. She wanted to go to her prom. This teenager summed up how the adolescents felt in this study: “ I don’t want to be ‘ the girl who has cancer’ .” These teenagers did not want to stand out nor to have negative attention. They just wanted their peers to see them as any other high school student.

**Wisdom** These adolescents had a different world view from those of their peers. Their priorities shifted as a result of their life-threatening illness. They had faced their mortality. These teens expressed a desire to be a better person, to help other families, and to make a difference in the world. Quite a few hoped to become pediatric oncologists. School was valued even more because they had to miss so much.

## **Parents’ Perspectives: Returning to School**

This research found that, in general, the experience of returning to school was very difficult. This study found that eight of the seventeen families had a positive experience, but with qualifiers. Those that had a good re-entry fell into three categories: 1) the child had been receiving special education services prior to diagnosis; 2) the

children were excellent students; 3) a teacher in one of their classes had a personal experience with cancer or other serious diseases; and 4) one person at the school made a major effort to care for the child. However, the last factor did not include having school collaboration. In analysis of the results, a re-entry was not considered successful if a parent had to constantly initiate conversation with an administrator at the school. The families liked the home-schooling teachers, but these teachers did not always receive the assignments from the school. Furthermore, results showed that the amount of parental involvement in the school prior to diagnosis did not predict a good relationship post-diagnosis. A major finding was that support from the school did not correlate with socioeconomics, ethnicity, or gender. A good relationship did not depend upon teaching experience, teacher's ethnicity, or teacher's education. Parental advocacy did not consistently make a difference. A review of parent and teacher demographics, surveys, and analysis of interviews supported these findings.

**What Was Difficult** Three areas caused problems with reintegration. First, there was very little systems integration between the families, the hospital and the school. Second, there was a lack of clear communication between the hospital, the school personnel, and parents, especially between the school and the parents. Three, there was a lack of understanding of the returning child's needs.

**Systems Integration** This refers to the continual interaction of the family, hospital, and school. The parents did not think to notify the school right away because they were so overwhelmed by the diagnosis. It would have been beneficial if the hospital could have a liaison to work with a point person at the school at the time of diagnosis. This could entail describing the child's treatment and possible effects. Teachers at Lucille Packard Children's Hospital described what steps they took to contact schools for high school students. Their process was described:

For high school kids, short term kids have work faxed to us, long term kids often either drop out of their school and temporarily enroll with us, and we do our best to teach whatever the home school is working on. We usually start with the counselor, who refers us to the individual teachers. Sometimes it is an administrator or the registrar who works with us. Depends on the school, but if we don't know, we start with the counselor... we have a permission form that must be signed before we can do anything with the student. This includes a transfer of information clause that allows us to call the school (Personal communication, August 20, 2010).

Furthermore, this teacher continued to say that:

We get pretty good follow through with schools - mainly because we have the kid sitting in the classroom with nothing to do, so we'll call the school until we get a response. At most, it takes a few days to get the work together, and in the meantime we'll assign things from our curriculum. It is definitely helpful if the parents have some kind of relationship with the school prior to diagnosis. Sometimes I'll call a school and the counselor already knows what's going on - this helps because they are usually more helpful. And sad to say, but if there is a student who is a poor performer or who has, in the past, missed a lot of school (not for medical reasons), the school is less likely to help.

Most responses from parents and children did not match this hospital teacher's experience. Results from interviews revealed that most of the children and parents did not

think the hospital was in contact with the school. The hospital teacher's last sentence stating the lack of response she gets if the child is not a good student supports the findings in this study.

As was discussed earlier in this paper, in five families, the siblings of the child with cancer had a difficult adjustment, acting out either at school or at home. An example of systems integration would have the hospitals inform schools about possible sibling reactions and how to help siblings adjust. Unfortunately, for the most part, each system operates as a single entity, focusing on its own tasks. Even when the hospital and the school did work together, there was no added education about what the child with cancer will need when he/she returns to school, nor was information disseminated for the child's classmates.

**Communication** There are four levels from which communication is rooted, the macrosystem, the exosystem, the mesosystem and the microsystem (Bronfenbrenner, 1979). The macrosystem represents the dominant culture with its social and economic capital. Laws and rules governing and overseeing individual institutions influence policies at the school level. It is the macrosystem that makes the policy that the school is supposed to follow. The second layer is the exosystem, comprised of separate institutions, like schools and hospitals. These institutions must act in accordance with the rules applicable to the culture of these systems. Often their policies affect the child, but do not directly interact with him. The mesosystem represents the connections between systems, with families and with the child. In this study, the interconnections between systems had a great deal of static. The last system, which has a relationship with all previous cultures, is the microsystem of the family and each of its members.

Parents believed that communication with the school would be productive because as a society we give professionals greater autonomy than other social groups on the assumption that their knowledge is valid and useful and that they will use it on behalf of their clients and the social good (Skrtic, 1995). As has been stated earlier in this paper, the professional relationship rests on a kind of mutual trust between the professional and the client (Skrtic, 1995). Trust leads to open communication.

On the surveys, the principals listed the services offered to the families. At least two were offered. Both the teachers and the parents did not have agreement with the principals or between themselves. For example, all, but one teacher, had no training concerning the needs of families when a child has a chronic illness such as cancer. The general education teachers had training in the areas of diversity and those students who are at-risk. This finding was replicated in another study where teachers in a dual credential program for both general education and special education said they were interested to learn about diversity (LePage, Nielsen, and Fearn, 2006). By "diversity", they meant learning about different cultures. The researcher taught a special education course for teachers which focused on families, diversity, and disability. When the topic of chronic illness was introduced, the students in the class said they had never thought about chronic illness as a form of diversity or disability that would need their attention within their roles as special educators, but welcomed the information.

A lack of knowledge was one of the reasons there often was unproductive and frustrating dialogue between the parents and the school. There was also a lack of communication internally between the school staff. First, the attendance office was either a support or caused a nightmare of problems. Some of the attendance office staff made

sure to check on the student and made sure the absences due to illness were recorded. Other attendance personnel were caught up in the web of technology where the student was automatically labeled as truant. The attendance office staff insisted that the record was "in the system" and could not be changed. The technology trumped the situation of the family.

Where a coordination of services was required, often, the teachers forgot to put accommodations in place, or refused to. At other times, when the principal agreed to let the teachers know when the child was returning and what was required, he or she did not follow through. In other cases, problems ended up with positive resolutions. For example, one boy told his coach that he had cancer, but this was not communicated to the rest of the faculty. This boy was home-schooled, but since he was absent, the computer run attendance office marked him truant, and he ended up with F's. It was not until the advisor and school counselor got involved that the problem was solved. A survey of 250 school counselors was taken in a large, urban school district (Kaffenberger, Edstrom, Hardison & Perdu, 2002). These counselors said they provided a wide range of services to facilitate school experiences for children with chronic illnesses. This was certainly not the experience of most families in this study. When school personnel were not required to put accommodations in place because the child was a good student, everything was fine. Since their children were high achievers, these parents did not need as much interaction with the school as those whose children were not high achieving. In some cases, the school staff was wonderful, calling the home, and sending cards to the hospital. When the parents talked about this kindness, they had smiles on their faces and, for a short time, their bodies relaxed.

Parents expected the principal or one of the administrative staff to work with them. One sister felt a lack of respect from the vice-principal. While some parents felt good about the principal's support, quite a few parents said the principal was uninvolved. Because of this dissatisfaction with the administration, the researcher was curious how another principal might see her role. Therefore, the researcher randomly selected a principal of a middle school in the northern bay area. This principal was very gracious and took the time to delineate the steps she would take if a child with cancer was returning to her school. The steps are as follows:

1. I'd learn all I could about the child, family, type of cancer, and his/her current condition.
2. Have a meeting with the family including the student, the school counselor, and the nurse to determine any needs.
3. If the condition and needs warranted it, I'd suggest a referral for a 504 plan.
4. In creating the student's schedule, I'd take into consideration getting him/her into classes with friends (if this is a student who had been here before) and with teachers that I know would work with us.
5. I'd call an all-teacher meeting and review all information, especially that which pertains to day-to-day impact on the student's academic and social/emotional needs.
6. I'd make sure a communication tool was developed to ensure that everyone was being kept in the loop. I'd have the counseling checking in regularly, as well as the nurse, if needed.

7. I, personally, as the principal, would also check in with the parents, student, and teachers to be sure that they are all okay.

This is an example of an educator who is proactive and shows caring not only for the family and the child, but also for her staff by educating them about the child's needs. Checking in with her staff, as well as with the family exemplifies Hanson's (2001) definition of an effective educator. Hansen views a teacher as a combination of person, conduct, and moral sensibility. The person part of a teacher is more important in teaching than the curricula and the technology. Conduct involves a pattern of behavior that supports meaningful teaching and learning. Moral sensibility fuses, harmonizes, and gives meaning to the first two.

The principal above equalizes power. She is willing to share her power. Unlike most of the principals in this study, this principal was willing to have a transactional, bi-directional relationship with the parents. All members of the team would feel as if they had power, bolstering self-esteem and even feelings of self-efficacy. The parents, in particular, would feel they had a positive relationship. Overall, this was not the case with the principals in the study. Parents felt powerless when trying to work with the school system in general and with the principals specifically. Sarason (1996) defines feelings of powerlessness to be when one feels that his/her ideas, opinions and interests do not deserve a hearing—that one is the object of discharge of power by others. In this study, parents were told to play the game with the rules decided by others.

As described above, effective collaboration is the key for parents to have a positive relationship with the schools. Where a positive collaboration took place, the parents in the study felt their children were being cared-for. Collaboration is the process used to reach goals that must be achieved through a group consensus (Bruner, 1991). It is a means to an end, not an end in itself. The desired end is more comprehensive and in education, the process can ensure the appropriate services for families. This study found that having all key stakeholders represented in the group was not enough. There needed to be follow-through and implementation of agreed upon services. When a child with cancer returns to school, it is important that all personnel involved in this child's school experience come up with the most beneficial accommodations. This means the family, including the child returning to school, a representative from the hospital, the principal, as the top administrator, the counselor, the school nurse and all the child's teachers. The principal above did include the counselor and school nurse as important participants in the re-entry process. In this study, when the school nurse and the counselor were involved, the family and the child had a positive experience. The importance of the school nurse and counselor is emphasized in a school re-entry intervention (Katz, Rubenstein, Hubert, & Blew, 1989; Katz, Varni, Rubenstein, Blew, & Hubert, 1992) and in proposed re-entry strategies (Kaffenberg, 2002).

**Knowledge Needed About Cancer** When school personnel are educated about childhood cancer, they would then know what having cancer means in terms of school attendance and learning. Since knowledge is power, teachers would feel a sense of self-efficacy. They will not ridicule a student who tells the class he has cancer. They would not need to have a personal experience with cancer to develop empathy. A first year teacher would have more patience with the student in his math class who needs less homework. Subject area packets would be left at the office for a parent to pick up. With this type of collaboration, there would be no missed connections.

**Caring for the Child** The philosophies of caring (Noddings, 1992) and moral pedagogy (Sockett, 1993) were the tools used for analyzing school support. When re-entry was successful, school personnel would actively want to know what accommodations were needed. For example, since special education teachers knew what difficulties the child had in school, they were extremely empathetic. They constantly kept in touch with the parents and the child whether the child was in school or not. Often school nurses were a source of support, insisting that the child come to her office to rest or by offering medical advice to parents so they would know what to ask doctors at the hospital. In this study, some teachers, such as an art teacher, mentored students which helped with school adjustment. Students looked forward to returning to school, so a caring teacher made a huge difference in their adjustment. These supportive actions by school staff exemplified in loco parentis, when teachers assume a parent-like role (Sockett, 1993).

Unfortunately, some homeschooled children were not allowed to go to school on days when they felt well. This was due to the rigidity of public school education policy. Under the umbrella of special education law, a law dictated by the dominant culture or macrosystem, the school was not supposed to let a child go back and forth from homeschooling to school. A child at home could receive a maximum five hours of school, one for each day of the school week. With this service, students were not allowed to simultaneously return to school.

Private school principals feared that the child would get ill from other students who came to school sick. It was demoralizing for both parents and their children.

### **Teens' Perspectives on Returning to School**

One finding was that all of the adolescents wanted to return to school and establish a normal teenage routine. Any distancing of friends was balanced by caring teachers who gave these students a sense of belonging. Even if a return to school did create problems, these teens were happy to be there, happy to be regular teenagers. Of the seven girls returning to school, three had to make new friends because, in their opinions, their friends prior to diagnosis had changed. One of the boys changed friends much to his parents' dismay because they thought his new friends were a bad influence. A boy with Asperger Syndrome had difficulty with his friends, but thought his teachers were good to him. However, in most cases, the boys' friends remained the same.

### **Application of Theory**

Both the Double ABCX and bioecological models were applied to the findings. The Double ABCX model has a main stressor event, Factor aA, which in this study, was the diagnosis of childhood cancer. Then came the pile-up of stressors as a result of the diagnosis. The first layer of stressors was the family's history of problems which were triggered by the child's illness. Other stressors included marital relationships, money problems, the need to reconfigure how the family worked together, and the need to understand how the culture of the hospital worked. Then, the parents had to interact with the school, the system most important to adolescents outside of their family microsystem. The Factor bB focused on the family resources. For example, was the parents' marriage a resource or a stressor? Relationships with extended family, friends, and the community were resources in many cases. The schools should have been a resource as well. The third factor, cC, was how families managed the original stressor, the cancer, their appraisals of how to deal with all their problems, and then, how they met the challenges of straddling

so many systems. Parents felt they coped well and were assertive when it came to their children's needs. Factor xX, represents how, over time, the family adapted to their added roles.

The bioecological model was a helpful tool for examining relationships among and between systems. The first system was that of the child's biology. The child's health was the catalyst for all the interactions that followed. The family reorganization started with the biological disequilibrium of the ill child which, in turn, threw the family microsystem off balance. The family required a reorganization of the parental roles. Usually, mothers were the caregivers of the children with cancer. The husband was responsible for work and the other children. In many cases, this proved to be difficult for siblings. The first interaction between systems occurred when families had to work with the medical field, specifically hospitals. Parents had to learn about both the culture of the hospital and the culture of childhood cancer. To act effectively, the parents had to learn the rules, values, beliefs, and ways of being in the hospital system. This meant knowing basics as disparate as what was required of them when chemotherapy commenced, to knowing where water was kept on the oncology wing of the hospital. Parents learned that they had to look for resources for themselves and other family members. For example, one parent was concerned about her child's siblings when she happened to be looking at a display case outside the oncology clinic. She saw a paper with suggestions for helping with the adjustment of siblings. This mother had to get a nurse, who had to call another person, to get someone to open the display case. In addition, many parents had to interact with the culture of the school in an entirely new role, that of parent advocate. Parents not only had to learn about policy regarding services for their children, but also inform the school district and the school about their child's needs. At times, the communication between and among systems was effective. At other times, the mesosystem's role as that of connection facilitator broke down. All systems were so overwhelmed and overworked that either incomplete information was transferred between systems, or no information was shared among and between systems. Medical staff was concerned with saving the child's life, hospital liaisons' work schedules were reduced, and schools were drowning with faculty and student problems along with the demands of paperwork for the school district and the state. The parent was burdened with wading through these systems.

The models were also appropriate to use with the teenagers. When applying the Double ABCX model, the Factor aA represents the child's diagnosis of cancer. The pile up of stressors would include uncertainty about his future, a worry about how he would function post-treatment, a concern about missing school and isolation from peers. Factor bB included resources available to the child. Resources included family members, church affiliation, and the network of family friends. Receiving up to date assignments from the school, having the school communicate with the support of cards and visits, and the companionship of peers were resources. If students did not have this support, they were unhappy and bored. Treatment was a resource because they hoped it would cure them, but it was also a stressor because of the side effects. Factor cC involved recognizing and accepting the limitations that their illness imposed upon them, recognizing supports and stressors and managing these supports and stressors. Factor xX represents the child's adaptation to his illness. Examples of this include believing that they will be cured and having positive self-esteem about their appearances due to treatment. Teens felt good when their friends came to visit. Others hid their concerns with a positive attitude along



with humor. It was a demoralizing stress when they were too tired to study or see friends.

The bioecological model was a good model to analyze the teenagers' ability to navigate the three systems in his life. First, they had to adapt to the new configuration of their families, and the need to be dependent upon their parents. Second, they had to adapt to the hospital, including the reality of treatment and its side effects. Third, they had to deal with school. Sometimes this task meant working with the hospital teacher and hoping that their school would get homework to the hospital.

### **Implications**

#### **Implication for Change**

This study revealed a need for policy changes at both the federal and state levels. The data pointed to the necessity of adding training about chronic illnesses, including cancer to a teacher education program. However policy change is very difficult. Sarason (1996) still hopes for educational reform, but he thinks there has been little reform since the 1970's when he first wrote about schools and the barriers to change. He states that it is a time in our country when the public is dissatisfied and disillusioned with our schools. This dejected feeling permeates all major systems in our society. There is a sense that our input has no power. In this study, at the comparatively minor system of the individual school, the lack of collaboration between parents with a child with cancer and the school is symptomatic of the greater breakdown of communication between citizens and the federal government. Furthermore, Sarason states that changing power relationships are destabilizing, that as individuals we resist change. The catastrophic diagnosis of childhood cancer forces families to adjust their world view. It is a shock to the familial and personal system. It is also unsettling to the school system. Macrocultural change has the advantage of slowly putting modifications into place. However, this change occurs over a very long time. In contrast, the family with a child with cancer must change abruptly.

For change to take place, there needs to be a paradigm shift, meaning the accepted worldview, the shared pattern of basic beliefs and assumptions about the nature of the world and how it works, must change (Skrtic, 1995). These assumptions tell us what is real and what is not, shapes our cultural identity and guides and justifies institutional practices. We are rarely conscious of our paradigms because they tend to surface mainly when they are changing. To make change in public policy, to create a more humane approach to chronic illness, specifically cancer, the paradigm of special education, under which this policy would fall, must be morally and politically viable in a democracy. This means that it is worth making changes, even when the educational system will be thrown into temporary disequilibrium. Since more and more children are coming to schools as survivors of life-threatening illnesses, changes would respect the needs of children with cancer.

Policy change would include letting students come to school when they can, listening to a family's needs and having productive collaboration. There is an important need for a point person at both the hospital and the school to exchange important information. Policy change impacts teacher education programs. Mirroring the lack of communication between all school personnel, this study underscores the need for dual general education/special education programs. This study suggests that both general education and special education teacher candidates be conversant in special education law, and understand family dynamics. Both types of teachers could then plan for student

needs for children with life-threatening illnesses, which represents a type of cultural diversity. Data from this study suggest that special education teachers and the general education teachers would benefit from collaborations about accommodations for this type of medical diversity as needed.

With current economic difficulties, the schools require teachers to take on many roles. Ideally, school counselors and/or school psychologists would take more of an active role in working with families with children with cancer (Kaffenberger, 2006; Power, DuPaul, Shapiro & Kazak, 2003). Again, because of fiscal reductions, a school is lucky to have a school psychologist who has time to do more than test students for eligibility for special education services. There are also not enough school counselors to adequately provide effective support to both families and teachers.

Increased knowledge for general education teachers would increase confidence when working with a child with cancer. It has been found that teachers are overwhelmed in two basic areas when a child with cancer re-enters school (Chekryn, Deegan, & Reid, 1987). The first area revolves around academic expectations, which includes obtaining information about how the child's treatment has affected learning. Teachers faced a dilemma concerning how to balance appropriate discipline with emotional support. The other major area had to do with the personal impact of this illness on the teachers. These teachers were upset and shocked. They saw cancer as life threatening, not knowing if the child would be alive and in school the following year. The teachers and counselors indicated they had no in-service training about the needs of a child with cancer. School counselors also need more training. Kaffenberger et. al (2002) found that 83% of the secondary high school counselors surveyed would welcome training. The results of the current study point to the fact that all school personnel, teachers and administrators, need to receive knowledge about children with chronic illnesses, especially cancer, as a part of their academic programs.

Changes can be made immediately on the intrapersonal and interpersonal levels. On the intrapersonal level, the school can prepare healthy peers to understand what their classmate is experiencing. Since a diagnosis of cancer brings up issues of mortality, the school could have a specific adult available who would provide a safe place for students to talk about their feelings. It would help if the hospital could send a liaison to educate the staff. The principal could make sure that the attendance office knows that the child has an excused absence. On an interpersonal basis, it is important for principals and teachers to meet with parents and/or children to prepare for a return to school. However, unlike what happened in this study, the school personnel would know exactly what is needed.

Relationships are built on positive interactions. Students in this study who had notes from their classmates, a poster brought by a teacher, teacher and classmate visits flourished psychologically. This is a time when schools can build upon moral development. For example, when the teenagers bet on when their peer would have a seizure, they should have been reprimanded and learned what caring means. If we want our teachers to practice moral pedagogy, then this means that the school must teach students what it means to be a moral, caring person. Small actions make big changes.

The ideal support is to provide an integration of services in order for the families' microsystems to flourish. This integration of systems heals the imbalance of services so that human needs can be fulfilled (See Figure 3). The figure below has the school

connected to the healthcare community, the primary caregiver and the child with cancer, and the rest of the immediate family. The school forms its own community consisting of school personnel, peers of the child, and its families. The school community can embrace the family in need with support. The family with the child with cancer would be able to feel bolstered by two communities at the same time, their own personal network and that of the school.

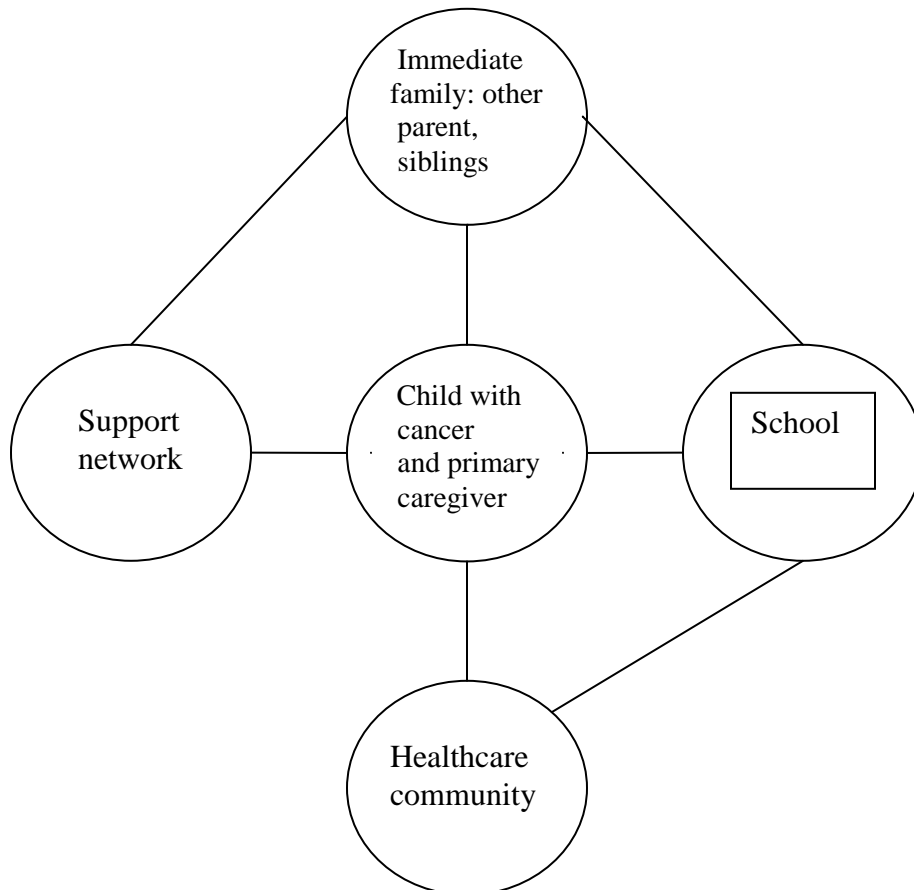


Figure 3. In this model, the school is connecting collaboratively with the medical community and the family to provide appropriate services.

The ultimate goal of this ideal system is to improve parent-school relationships, to provide safety for professionals to extend caring, and for families and their children to feel cared-for.

**Implications for Further Research**

The findings of this study make it clear that teachers have underlying experiences that influence their perceived ability to work with families who have a child with cancer.

A qualitative study interviewing teachers about their feelings about working with a child with cancer would help to elucidate the needs of the teaching staff. Another form of research could be to enact an intervention for teachers so they would understand, not only the child and family's needs, but also their own. This could be in the form of support groups. The personal attitude of principals was not examined in this study. The adaptation of principals to having families with a child with cancer was expressed from the perceptions of the parents and children in this study. How do principals envision their roles when working with staff and families? Another study of the reintegration process could involve evaluating the different types of procedures in various schools when a child returns to school. Results could ascertain what methods are most successful. An important study would involve analysis of collaboration from elementary school through high school. What types of steps need to be in place to advocate for policy reform? How do both school personnel and families envision a clarity of process? There are many avenues for future research. What will it take to practice the philosophy of *in loco parentis*? The most important element is to discover ways to optimally nurture trust and caring via the building of relationships.

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# Appendix A

Recruitment Flyer  
Volunteers Needed for Study

My name is Shelley Nielsen. I am a doctoral student in the Joint Doctoral Program in Special Education at the University of California, Berkeley and San Francisco State University. I am currently working on my dissertation which focuses on parents of children with cancer. The goal of this study is to inform schools how best to meet the needs of families who have or had a child with cancer. I need parents of adolescent children who are currently being treated for cancer or have finished treatment within the last five years. This study mainly involves interviews. If you are interested, the research study will be explained in detail over the phone. Parents may choose how much they wish to participate. All participation will be completely confidential.

If you are interested in participating, please contact me either by phone or email. My phone number is (650)344-8804. My email is shellejysr@astound.net.

## Parent Volunteers for School Re-entry Study



**Who** Parents of Children with Cancer grades 7-12 within 5yrs of treatment

**Why** To determine how schools can best meet family needs

**How** Interviews conducted by Shelley Nielsen, Doctoral Student

**When** At your convenience with a special family gift card included

**Where** Your home/office or to be determined

If interested in learning more about the study or  
participating contact:

Shelley Nielsen vMail 650.344.8804 or eMail  
[shelleyjsr@astound.net](mailto:shelleyjsr@astound.net)

For general information about participant rights, contact  
1.866.680.2906

## Letter of Consent

My name is Shelley Nielsen. I am a graduate student in the Joint Doctoral Program in Special Education at the University of California at Berkeley and San Francisco State University. I would like to invite you to take part in my research study, which examines families who have had a child with cancer and what they would like schools to know in order to support you and your child.

If you agree to take part in my research, you will be asked to take part in two surveys and in an interview. The interview will last about an hour, at a time and place of your choosing. You will receive a copy of the interview questions prior to our meeting. With your permission, the interview will be audio taped. I may ask to contact you by telephone or mail if there are any follow-up questions I have after our interview. With your permission, I would also like to examine any school or medical data relating to this research.

There may be a few risks to you from taking part in this research. There is a small possibility of loss of privacy. Every effort will be made to prevent this. For a time, this survey and interview may cause you to re-experience a difficult time in your life. The benefit to you may be that you can tell your story and be heard with empathy. It is hoped that the research will benefit others who have children with cancer while navigating the school system.

All of the information that I obtain from you during the research will be kept confidential. I will follow current Committee for the Protection of Human Subjects guidelines for research and confidentiality in order to maintain maximum participant confidentiality and to minimize the small chance of loss of privacy. Since I have contacted you by telephone, your information has been de-identified and encrypted in compliance with current CPHS guidelines as will surveys, interviews, and medical and school information. Only I will have access to an identity data set with a secure location key. Identity-only data sets and de-identified data sets will be stored separately and in secure locations according to CPHS policy. If information from this study is published or presented at scientific meetings, your names and other personal information will not be used. I will discuss it with you if I decide to retain this data, after the immediate project is completed, for possible use in future projects by me or others. After this research is completed, I may also save the tape recordings for use in future research by others or myself. However the same confidentiality guarantees given here will apply to future storage and use. Although I will keep your name confidential, you may still be identifiable to others on the audio tapes.

Your participation in this research is voluntary. You are free to refuse to take part. You may refuse to answer any questions and may stop taking part in the study at any time.

If you have any questions about the research, you may telephone me, Shelley Nielsen, at (650) 344-8804 or contact me by email: shelleyjsr@astound.net. If you agree to take part in the research, please sign the form below. Please keep the other copy of this agreement for your future reference.

If you have any question regarding your treatment or rights as a participant in this research project, please contact the University of California at Berkeley's, Committee for Protection of Human Subjects at (510)642-7461, subjects@berkeley.edu.

I/we have read this consent form and agree to take part in this research.

---

Signature

---

Date

---

Signature

---

Date

Audio Records Release Form

As part of this project, I will be making an audio recording of you while you participate in the research. Please indicate below what uses of these records you are willing to consent to. This is completely up to you. I will only use the records in ways that you agree to. In any use of these records, your name will not be identified.

I will follow current Committee for the Protection of Human Subjects guidelines for research and confidentiality in order to maintain maximum participant confidentiality and to minimize the small chance of loss of privacy. The same confidentiality guarantees given here will apply to future storage and use. Although I will keep your name confidential, you may still be identifiable to others on the audio tapes.

1. The records can be studied by the research team for use in the research project.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

2. The records can be used for educational/scientific publications.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

3. The records can be heard at meetings of educators or scientists interested in the study of the family, childhood cancer, and education.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

4. The records can be heard in classrooms to graduate students.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

5. The records can be heard in public presentations to nonscientific groups.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

I/we have read the above description and give my consent for the use of the records as indicated above.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_



Medical Information Release Form

As a part of this project, I will need to review medical data that you may have from your child's doctors and hospital of treatment. I will follow current Committee for the Protection of Human Subjects guidelines for research and confidentiality in order to maintain maximum participant confidentiality and to minimize the small chance of loss of privacy. Your name, child's name, medical personnel or hospital will not be identified. Please indicate below what use of these records you are willing to consent to. This is completely up to you. I will only use the information in ways that you agree to.

1. The information can be studied by the research team for use in the research project.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

2. The information can be used for educational/scientific publications.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

3. The records can be shared at meeting of educators/scientists interested in the study of families, childhood cancer, and schools.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

4. The information can be shared in classrooms to graduate students.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

5. The information can be shared in public presentations to nonscientific groups.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

I/we have read the above description and give consent for the use of the information as indicated above.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Educational Information Release Form

As a part of this project, I will need to review educational data from your child's school. This information will be strictly confidential. I will follow current Committee for the Protection of Human subjects guidelines for research and confidentiality in order to maintain maximum participant confidentiality and to minimize the small chance of loss of privacy. Your child's name and school personnel will not be identified. Please indicate below what use of these records you are willing to consent to. This is completely up to you. I will only use the information in ways that you agree to.

1. The information can be studied by the research team for use in the research project.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

2. The information can be used for educational/scientific publications.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

3. The records can be shared at meetings of educators/scientists interested in the study of families, childhood cancer, and schools.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

4. The information can be shared in classrooms to graduate students.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

5. The information can be shared in public presentations to nonscientific groups.

Initials \_\_\_\_\_ Initials \_\_\_\_\_

I/we have read the above description and give consent for the use of the information as indicated above.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_.



Parent Permission Form  
Parental Consent Form for Child Participation in Research  
School Response to Families Who Have a Child with Cancer

Introduction and Purpose

My name is Shelley Nielsen. I am a doctoral student at the University of California, Berkeley. I am the lead investigator in this study under the guidance of my faculty sponsor, Dr. Anne Cunningham in the Department of Special Education. I would like to invite your child to take part in my research study, which is concerned with how schools respond to a child and his/her family upon school re-entry.

Procedures

If you agree to have your child participate in my research, I will conduct an interview with him/her at a time and location of your choice. The interview will involve questions about how your child has experienced cancer emotionally, socially, and academically. It should last about 20 minutes. With your permission, I will audiotape and take notes during the interview. The taping is to accurately record the information your child provides, and will be used for transcription purposes only. If you choose for your child not to be audiotaped, I will take notes instead. If you agree to having your child audiotaped but he/she feels uncomfortable at any time during the interview, I can turn off the tape recorder at your or your child's request. Or if your child doesn't wish to continue, you can stop the interview at any time.

I expect to conduct only one interview; however, follow-ups may be needed for added clarification. If so, I will contact you by mail/phone to request this. Also, I will do this if I need more information when I analyze the data.

Benefits

It is hoped that in the future, the research will help other families in the same situation as yours. Although no direct benefit from taking part in this study can be promised, your child may feel good about helping others in this way

Risks/Discomforts

A potential risk is that your child may feel uncomfortable and that the questions may cause him/her to re-experience this difficult time. Your child is free to decline to answer any questions or stop the interview at any time. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. (See below for more detail.)

Confidentiality

Your child's study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. All data will be encoded, and identifying information, surveys, interview notes, and audiotapes will be kept in a locked file cabinet. Only I will have access to this information. After this research is completed, I may save the study data and tape recordings for use in future research by myself or others, for up to 5 years. However, the same measures for confidentiality given here will apply to future storage

and use. (Please note that although I will keep names confidential, voices may still be identifiable to others on the audio tapes.)

Compensation

Your child will receive a \$30 gift card for participating in this study.

Rights

Participation in research is completely voluntary. You are free to decline for your child to take part in the project. Your child can decline to answer any questions and is free to stop taking part in the project at any time. Whether or not you choose for your child to participate in the research and whether or not your child chooses to answer a question or continue participating in the project, this will have no effect on his/her medical treatment or grades at school.

Questions

If you have any questions about this research, please feel free to contact me. I can be reached either at (650) 344-8804 or [shelleyjsr@astound.net](mailto:shelleyjsr@astound.net).

If you have any questions about your rights or treatment as a research participant in this study, please contact the University of California at Berkeley's Committee for Protection of Human Subjects at 510-642-7461, or e-mail [subjects@berkeley.edu](mailto:subjects@berkeley.edu).

\*\*\*\*\*

PERMISSION

You will be given a copy of this consent form to keep for your own records. If you wish your child to participate in this study, please sign and date below.

\_\_\_\_\_  
Child's Parent Name(please print)

\_\_\_\_\_  
Child's Parent Signature

\_\_\_\_\_  
Date



Child Assent to Participate in Research  
School Response to Families who have a Child with Cancer

1. What is this study about? (Purpose)

My name is Shelley Nielsen. I am a doctoral student at the University of California, Berkeley in the School/Department of Special Education. I would like to invite you to take part in my research study. The purpose of the research is to learn how families like yours can help their children to have the best school experience possible. You will be asked to tell me about how you feel your school has treated you as a child with cancer. You can tell me whatever is important to you.

2. What else is going to happen? (Procedure)

If you agree to participate in my research, and your parents also agree, I will conduct an interview with you at a time and location of your and your parents' choice. It should last about 20 minutes. If it is OK with you, I will audiotape and take notes during the interview. The taping is so I don't forget anything you've said. If you choose not to be audiotaped, I will take notes instead. If you agree to being audiotaped but feel uncomfortable at any time during the interview, I can turn off the tape recorder if you ask. If you don't wish to continue, you can stop the interview at any time.

3. Can anything good happen to me? (Benefits)

We can't promise any direct benefit to you, but we hope the things we learn from this study will help other children who have cancer and are going to school. So, it might make you feel good to be helping other kids and families like yours.

4. Can anything bad happen to me? (Risks/Discomforts)

Nothing bad will happen to you. It might be hard to talk about having cancer. If it is, you don't have to continue or you can skip any questions you don't want to answer. You can tell your parents if you are uncomfortable talking to me.

5. Will anyone know I am in the study? (Confidentiality)

No one will know your name. Your information is private and I will not share who you are with anyone.

6. Who can I talk to about the study? (Contact Information)

If you have any questions about the study or any problems to do with the study, you can talk to your parents or you can contact me, the Lead Investigator, Shelley Nielsen at (650) 344-8804 or shelleyjsr@astound.net.

7. What will I receive for taking part in the study? (Compensation)

You will be given a gift card of your choice in the amount of \$30 for your participation in the study.





Parent Permission to Give Surveys to School Personnel  
Consent to Participate in Research  
School Response to Families Who Have a Child with Cancer

Introduction and Purpose

My name is Shelley Nielsen. I am a doctoral student at the University of California, Berkeley. I am the lead investigator in this study under the guidance of my faculty sponsor, Dr. Anne Cunningham, in the Department of Special Education. I would like to invite you to take part in my research study, which is concerned with how schools respond to a child with cancer and his/her family upon school re-entry.

Procedures

If you agree to participate in my research, I will conduct an interview with you at a time and location of your choice. The interview will involve questions about how you have experienced cancer emotionally, socially, and academically. It should last about 20 minutes. With your permission, I will audiotape and take notes during the interview. The taping is to accurately record the information you provide. If you choose not to be audiotaped, I will take notes instead. If you agree to being audiotaped but feel uncomfortable at any time during the interview, I can turn off the tape recorder at your request. Or if you don't wish to continue, we can stop the interview at any time.

I expect to conduct only one interview; however, follow-ups may be needed for added clarification. If so, I will contact you by mail/phone to request this. Also, I will do this if I need more information when I am analyzing the data.

Benefits

It is hoped that in the future, the research results will help other families in the same situation as yours. Although no direct benefit from taking part in this study can be promised, you may feel good about helping others in this way.

Risks/Discomforts

A potential risk is that you may feel uncomfortable and that the questions may cause you to re-experience this difficult time. You are free to decline to answer any questions or stop the interview at any time. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. (See below for more detail.)

Confidentiality

Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. All data will be encoded, and identifying information, surveys, interview notes, and audiotapes will be kept in a locked file cabinet. Only I will have access to this information. After this research is completed, I may save the study data and tape recordings for use in future research by myself or others, for up to 5 years. However, the same measures for confidentiality described above will apply to future storage and use. (Please note that although I will keep names confidential, voices may still be identifiable to others on the audio tapes.)

Compensation

You will receive a \$30 gift card for participating in this study.

Rights

Participation in research is completely voluntary. You are free to decline to take part in the project, answer any questions, or stop taking part in the study at any time. Whether or not you choose to do any of these things, this will have no effect on your medical treatment or grades at school.

Questions

If you have any questions about this research, please feel free to contact me. I can be reached at either at 650-344-8804 or [shelleyjsr@astound.net](mailto:shelleyjsr@astound.net).

If you have any questions about your rights or treatment as a research participant in this study, please contact the University of California at Berkeley’s Committee for Protection of Human Subjects at 510-642-7461, or e-mail [subjects@berkeley.edu](mailto:subjects@berkeley.edu).

\*\*\*\*\*

CONSENT

You will be given a copy of this consent form to keep for your own records. If you wish to participate in this study, please sign and date below.

\_\_\_\_\_  
Participant Name (please print)

\_\_\_\_\_  
Participant Signature (must be 18 or older)

\_\_\_\_\_  
Date





## Teacher Introduction Letter

Dear Teacher,

My name is Shelley Nielsen. I am a student in the Joint Doctoral Program in Special Education with the University of California, Berkeley, and San Francisco State University. I am currently working on my dissertation which examines school response towards families and children with cancer. As you know, \_\_\_\_\_ is currently undergoing treatment for cancer. His/Her parents/caregivers, \_\_\_\_\_ and \_\_\_\_\_ have signed the enclosed consent form for your participation in this research. You will be asked to fill out a self-administered, precoded survey. Neither you, your student, nor his/her family will be identified.

If you have any questions about the study or the survey, please feel free to contact me either at (650) 344-8804, or the School of Special Education at UC Berkeley at (510) 643-6871. Also feel free to email me at [shelleyjsr@astound.net](mailto:shelleyjsr@astound.net).

Please contact me to let me know if you are willing to participate in this study. If you agree to participate, I will send you a consent form to be filled out and returned to me in a stamped, addressed envelope. Then I will send the survey.

Thank you for your help.

Sincerely,  
Shelley Nielsen

## Principal Introduction Letter

Dear Principal,

My name is Shelley Nielsen. I am a student in the Joint Doctoral Program in Special Education with the University of California, Berkeley, and San Francisco State University. I would appreciate you taking about 20 minutes to complete this survey about your school for my dissertation. The subject of my dissertation is school response to families with children with cancer. The study will give educators, policy-makers, practitioners, and parents important information about families and their children's experiences. This will also provide the schools and families ways to contribute to student performance. I am also interested in how schools cope with having students with such a serious illness, such as cancer.

Please return the completed survey as soon as possible in the enclosed postage-paid envelope. Please be assured that your answers will be completely confidential. The survey is encoded so that no information will be reported that identifies you or this school. Since this is a one-time, self-administered, general survey, your completion of this form will be your consent.

I appreciate you taking the time from your busy schedule to fill out this survey. In return, at the end of this survey, I am offering you a small token of my appreciation. When you have completed this survey, please fill out the information sheet with its separate addresses, stamped envelope so I can send this gift to you. Returning this sheet separately retains confidentiality.

If you have any questions about the study or the survey, please feel free to contact me either at (650) 344-8804, or the School of Special Education at UC Berkeley at (510) 643-6871. Also feel free to email me at [shelleyjsr@astound.net](mailto:shelleyjsr@astound.net).

Thank you in advance for your contribution to this important study.

Sincerely,  
Shelley Nielsen

Teacher Consent Form

I give my consent to Shelley Nielsen to send me the self-administered, encoded survey that was described to me on the telephone. This information will be strictly confidential. The researcher will follow current Committee for the Protection of Human subjects guidelines for research and confidentiality in order to maintain maximum participant confidentiality and to minimize the small chance of loss of privacy. My name will not be identified. I will indicate below what use of these results I am willing to consent to. I know this is completely up to me. I am aware that the information will only be used in ways that I agree to. I am aware that I will receive a gift card for filling out the survey.

I agree to fill out this survey.

\_\_\_\_\_  
Name Date

1. The information can be studied by the research team for use in the research project.

Initials Initials

2. The information can be used for educational/scientific publications.

Initials Initials

3. The records can be shared at meetings of educators/scientists interested in the study of families, childhood cancer, and schools.

Initials Initials

4. The information can be shared in classrooms to graduate students.

Initials Initials

5. The information can be shared in public presentations to nonscientific groups.

Initials Initials

I have read the above description and give consent for the use of the information as indicated above.

Signature\_\_\_\_\_ Date\_\_\_\_\_

# Appendix B

Female Caregiver Survey

Please answer the questions below. If you need more space, please continue on the back of this form.

Name of Person filling out survey \_\_\_\_\_

Family Information

1. Your Relationship to Child

Biological/Adoptive Mother \_\_\_\_\_

Stepmother \_\_\_\_\_

Foster parent \_\_\_\_\_

Legal Guardian \_\_\_\_\_

Sister/Step sister \_\_\_\_\_

Aunt \_\_\_\_\_

Grandmother \_\_\_\_\_

Other (Specify) \_\_\_\_\_

2. Child's ethnicity:

White \_\_\_\_\_

African-American or Black \_\_\_\_\_

Latino \_\_\_\_\_

American Indian \_\_\_\_\_

Alaskan Native \_\_\_\_\_

Native Hawaiian \_\_\_\_\_

Asian \_\_\_\_\_

Other Pacific Islander \_\_\_\_\_

Mixed ethnicity (please specify) \_\_\_\_\_

2a. Child's Gender F \_\_\_\_\_ M \_\_\_\_\_

3. Child's Birth Date

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

mm dd yy

4. Child's age at time of diagnosis: \_\_\_\_\_

Date of diagnosis \_\_\_\_\_

5. What was the child's living situation at the time of diagnosis?

Living with both parents \_\_\_\_\_

Shared custody between two separated/divorced parents \_\_\_\_\_

Foster home \_\_\_\_\_

Group home \_\_\_\_\_

Grandparents \_\_\_\_\_

Other relatives (please specify) \_\_\_\_\_

Legal guardian (please specify) \_\_\_\_\_

Other \_\_\_\_\_

If different, where is the child living now? \_\_\_\_\_

6. What is your ethnicity?

White

African-American or Black

Latino

American Indian

Alaskan Native

- Native Hawaiian
- Asian
- Please give specific ethnic background \_\_\_\_\_
- Other Pacific Islander
- Mixed ethnicity (please specify)

7. What was your income when your child was diagnosed?
  - a. 0-\$25,000
  - b. \$25,001-\$50,000
  - c. \$50,0001-\$75,000
  - d. \$75,001-\$110,000
  - e. \$110,001-\$150,000
  - f. \$150,001 and up
8. Your Educational Background
  - a. Years of School Attended \_\_\_\_\_
  - b. GED or High School Equivalency
  - c. High school graduate
  - d. AA degree
  - e. B.A. degree
  - f. Post-Graduate degree: Please specify \_\_\_\_\_
9. Your occupation: \_\_\_\_\_
10. Did you have health insurance when your child was diagnosed? Yes \_\_\_ No \_\_\_  
 If yes, were all of your child's medical expenses fully covered?  
 How much has not been covered so far? \_\_\_\_\_  
 Were there any changes in your medical insurance?
11. How many children were in your family at the time your child was diagnosed with cancer? \_\_\_\_\_  
 Number of girls \_\_\_ Number of boys \_\_\_  
 Ages of girls: \_\_\_\_\_ Ages of boys \_\_\_\_\_

Your Child's Cancer

1. What type of cancer does and/or did your child have?
  - Non-Hodgkins Lymphoma \_\_\_
  - Hodgkins \_\_\_\_\_
  - Leukemia \_\_\_\_\_
  - Osteosarcoma \_\_\_\_\_
  - Brain Tumor \_\_\_\_\_
  - Other \_\_\_\_\_
2. From the date of diagnosis to the present, what has been the length of your child's treatment?
  - 0-3 months \_\_\_\_\_
  - 3-6 months \_\_\_\_\_
  - 7-12 months \_\_\_\_\_
  - 13- 18 months \_\_\_\_\_
  - 19- 24 months \_\_\_\_\_
  - Other: \_\_\_\_\_
 Is this treatment ongoing? Yes \_\_\_ No \_\_\_\_\_
- 2b. What types of treatment is or has your child received?

Check all that apply:

Surgery \_\_\_

Chemotherapy \_\_\_

Radiation \_\_\_\_\_

Bone Marrow Transplant \_\_\_\_\_

Blood Transfusion \_\_\_\_\_

Other \_\_\_\_\_

#### Education and Your Child's Illness

1. What grade was your child in when he/she received his/her diagnosis? \_\_\_\_\_  
What grade is your child in now? \_\_\_\_\_
2. Prior to your child's diagnosis, did your child have an IEP or 504 plan?  
If so, please describe \_\_\_\_\_  
\_\_\_\_\_
3. Was your child in :  
public school \_\_\_  
private school \_\_\_
- 3b. Did your child return to the same school after diagnosis?  
If not, why? \_\_\_\_\_  
\_\_\_\_\_
- 3c. Where does your child go to school now? \_\_\_\_\_
4. Was the school notified of your child's diagnosis? Yes \_\_\_ No \_\_\_
5. Who notified the school about your child's diagnosis and treatment?  
Check all that apply:  
Myself \_\_\_  
Spouse/partner \_\_\_  
Hospital personnel \_\_\_\_\_
- 5a. Before your child's diagnosis, who had the most interaction with your child's school?  
Myself \_\_\_  
Spouse/ partner \_\_\_  
Other (please specify who) \_\_\_\_\_
- 5b. Before your child's diagnosis, what was your relationship with the school?  
There was none \_\_\_  
I only went to the school if the teacher or principal requested a meeting \_\_\_  
I went to specific school related events \_\_\_  
Please check all that apply:  
Back-to-School Night \_\_\_  
School programs that my child was in \_\_\_  
PTA meetings \_\_\_\_\_  
School-site council meetings \_\_\_\_\_  
Parent-Teacher conferences \_\_\_  
Other school-related events \_\_\_  
Please name these \_\_\_\_\_  
I was very active in the school \_\_\_\_\_  
Please check all that apply:  
Back-to-School Night \_\_\_  
School programs that my child was in \_\_\_



PTA meetings \_\_\_\_\_  
School-site council meetings \_\_\_\_\_  
Parent-Teacher conferences \_\_\_\_\_  
Volunteered in my child's classroom \_\_\_\_\_  
What did you do? \_\_\_\_\_  
Other types of involvement (Please Name) \_\_\_\_\_

5C. After your child's diagnosis, what was your relationship with the school:  
Please check all that apply.

There was none \_\_\_\_\_  
I only went to the school if the teacher or principal requested a meeting \_\_\_\_\_  
I went to specific school related events \_\_\_\_\_

Please check all that apply:  
Back-to-School Night \_\_\_\_\_  
School programs that my child was in \_\_\_\_\_  
PTA meetings \_\_\_\_\_  
School-site council meetings \_\_\_\_\_  
Parent-Teacher conferences \_\_\_\_\_  
Other school-related events \_\_\_\_\_  
Please name these \_\_\_\_\_

I was very active in the school \_\_\_\_\_

Please check all that apply:  
Back-to-School Night \_\_\_\_\_  
School programs that my child was in \_\_\_\_\_  
PTA meetings \_\_\_\_\_  
School-site council meetings \_\_\_\_\_  
Parent-Teacher conferences \_\_\_\_\_  
Volunteered in my child's classroom \_\_\_\_\_  
What did you do? \_\_\_\_\_  
Other types of involvement (Please Name) \_\_\_\_\_

6. What was the school's response to your child's diagnosis?

Check all that apply:  
The principal called home \_\_\_\_\_  
The teacher called home \_\_\_\_\_  
How many times did the teacher (s) contact you or your child :  
1 time \_\_\_\_\_  
2-4 times \_\_\_\_\_  
Once a week \_\_\_\_\_

The school offered to send schoolwork home \_\_\_\_\_  
Schoolwork was sent home once a week \_\_\_\_\_  
The school offered to set up home schooling \_\_\_\_\_  
The school counselor/psychologist offered to meet with you \_\_\_\_\_  
1 time \_\_\_\_\_  
Once a month \_\_\_\_\_  
Once a month throughout the school year \_\_\_\_\_  
Other \_\_\_\_\_

The school encouraged classmates to keep in touch with your child \_\_\_\_\_

Once a week \_\_\_\_

Other \_\_\_\_

On a scale from 1 to 5, please circle the number which applies to your feelings of support by the following people at the time of diagnosis and during your child's treatment. How would you rate:

1. Your child's classroom teacher or homeroom teacher?

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

If your child is in middle school or high school, please rate the teacher of each subject.

Subject: English

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: Math

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: Science

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: History

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: P.E.

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
Subject or Other: _____					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The classroom aide					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school principal					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school counselor					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school psychologist					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The vice-principal or dean					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The child's coach for a sport					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable

supportive	supportive	support	supportive	support	Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The Special Education teacher					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The speech/language teacher					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

Male Caregiver Survey

Please answer the questions below. If you need more space, please continue on the back of this form.

Name of Person filling out survey \_\_\_\_\_

Family Information

1. Your Relationship to Child

Biological/Adoptive Father \_\_\_\_\_

Stepfather \_\_\_\_\_

Foster parent \_\_\_\_\_

Legal Guardian \_\_\_\_\_

Brother/Step brother \_\_\_\_\_

Uncle \_\_\_\_\_

Grandfather \_\_\_\_\_

Other (Specify) \_\_\_\_\_

2. Child's ethnicity:

White \_\_\_\_\_

African-American or Black \_\_\_\_\_

Latino \_\_\_\_\_

American Indian \_\_\_\_\_

Alaskan Native \_\_\_\_\_

Native Hawaiian \_\_\_\_\_

Asian \_\_\_\_\_

Other Pacific Islander \_\_\_\_\_

Mixed ethnicity (please specify) \_\_\_\_\_

2a. Child's Gender F \_\_\_ M \_\_\_

3. Child's Birth Date

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

mm dd yy

4. Child's age at time of diagnosis: \_\_\_\_\_

Date of diagnosis \_\_\_\_\_

5. What was the child's living situation at the time of diagnosis?

Living with both parents \_\_\_

Shared custody between two separated/divorced parents \_\_\_\_\_

Foster home \_\_\_

Group home \_\_\_

Grandparents \_\_\_

Other relatives (please specify) \_\_\_\_\_

Legal guardian (please specify) \_\_\_\_\_

Other \_\_\_\_\_

If different, where is the child living now? \_\_\_\_\_

6. What is your ethnicity?

White

African-American or Black

Latino

American Indian

Alaskan Native

- Native Hawaiian
- Asian
- Please give specific ethnic background \_\_\_\_\_
- Other Pacific Islander
- Mixed ethnicity (please specify)

7. What was your income when your child was diagnosed?
  - a. 0-\$25,000
  - b. \$25,001-\$50,000
  - c. \$50,0001-\$75,000
  - d. \$75,001-\$110,000
  - e. \$110,001-\$150,000
  - f. \$150,001 and up
8. Your Educational Background
  - a. Years of School Attended \_\_\_\_\_
  - b. GED or High School Equivalency
  - c. High school graduate
  - d. AA degree
  - e. B.A. degree
  - f. Post-Graduate degree: Please specify \_\_\_\_\_
9. Your occupation: \_\_\_\_\_
10. Did you have health insurance when your child was diagnosed? Yes \_\_\_ No \_\_\_  
 If yes, were all of your child's medical expenses fully covered?  
 How much has not been covered so far? \_\_\_\_\_  
 Were there any changes in your medical insurance?
11. How many children were in your family at the time your child was diagnosed with cancer? \_\_\_\_\_  
 Number of girls \_\_\_ Number of boys \_\_\_  
 Ages of girls: \_\_\_\_\_ Ages of boys \_\_\_\_\_

Your Child's Cancer

1. What type of cancer does and/or did your child have?
    - Non-Hodgkins Lymphoma \_\_\_
    - Hodgkins \_\_\_\_\_
    - Leukemia \_\_\_\_\_
    - Osteosarcoma \_\_\_\_\_
    - Brain Tumor \_\_\_\_\_
    - Other \_\_\_\_\_
  2. From the date of diagnosis to the present, what has been the length of your child's treatment?
    - 0-3 months \_\_\_\_\_
    - 3-6 months \_\_\_\_\_
    - 7-12 months \_\_\_\_\_
    - 13- 18 months \_\_\_\_\_
    - 19- 24 months \_\_\_\_\_
    - Other: \_\_\_\_\_
- Is this treatment ongoing? Yes \_\_\_ No \_\_\_\_\_
- 2b. What types of treatment is or has your child received?

Check all that apply:

Surgery \_\_\_

Chemotherapy \_\_\_

Radiation \_\_\_\_\_

Bone Marrow Transplant \_\_\_\_\_

Blood Transfusion \_\_\_\_\_

Other \_\_\_\_\_

Education and Your Child's Illness

1. What grade was your child in when he/she received his/her diagnosis? \_\_\_\_\_  
What grade is your child in now? \_\_\_\_\_

2. Prior to your child's diagnosis, did your child have an IEP or 504 plan?  
If so, please describe \_\_\_\_\_

3. Was your child in :  
public school \_\_\_  
private school \_\_\_

3b. Did your child return to the same school after diagnosis?  
If not, why? \_\_\_\_\_

3c. Where does your child go to school now? \_\_\_\_\_

4. Was the school notified of your child's diagnosis? Yes \_\_\_ No \_\_\_

5. Who notified the school about your child's diagnosis and treatment?

Check all that apply:

Myself \_\_\_

Spouse/partner \_\_\_

Hospital personnel \_\_\_\_\_

5a. Before your child's diagnosis, who had the most interaction with your child's school?

Myself \_\_\_

Spouse/ partner \_\_\_

Other (please specify who) \_\_\_\_\_

5b. Before your child's diagnosis, what was your relationship with the school?

There was none \_\_\_

I only went to the school if the teacher or principal requested a meeting \_\_\_

I went to specific school related events \_\_\_

Please check all that apply:

Back-to-School Night \_\_\_

School programs that my child was in \_\_\_

PTA meetings \_\_\_\_\_

School-site council meetings \_\_\_\_\_

Parent-Teacher conferences \_\_\_

Other school-related events \_\_\_

Please name these \_\_\_\_\_

I was very active in the school \_\_\_\_\_

Please check all that apply:

Back-to-School Night \_\_\_

School programs that my child was in \_\_\_

- PTA meetings\_\_\_\_\_
- School-site council meetings\_\_\_\_\_
- Parent-Teacher conferences\_\_\_\_\_
- Volunteered in my child's classroom\_\_\_\_
- What did you do?\_\_\_\_\_
- Other types of involvement (Please Name)\_\_\_\_\_

5C. After your child's diagnosis, what was your relationship with the school:  
Please check all that apply.

- There was none\_\_\_\_\_
- I only went to the school if the teacher or principal requested a meeting\_\_\_\_\_
- I went to specific school related events\_\_\_\_\_

Please check all that apply:

- Back-to-School Night\_\_\_\_\_
- School programs that my child was in\_\_\_\_\_
- PTA meetings\_\_\_\_\_
- School-site council meetings\_\_\_\_\_
- Parent-Teacher conferences\_\_\_\_\_
- Other school-related events\_\_\_\_\_
- Please name these\_\_\_\_\_

I was very active in the school\_\_\_\_\_

Please check all that apply:

- Back-to-School Night\_\_\_\_\_
- School programs that my child was in\_\_\_\_\_
- PTA meetings\_\_\_\_\_
- School-site council meetings\_\_\_\_\_
- Parent-Teacher conferences\_\_\_\_\_
- Volunteered in my child's classroom\_\_\_\_
- What did you do?\_\_\_\_\_
- Other types of involvement (Please Name)\_\_\_\_\_

6. What was the school's response to your child's diagnosis?

Check all that apply:

- The principal called home\_\_\_\_\_
- The teacher called home\_\_\_\_\_

How many times did the teacher (s) contact you or your child :

- 1 time\_\_
- 2-4 times\_\_
- Once a week\_\_\_\_\_

The school offered to send schoolwork home\_\_\_\_\_

    Schoolwork was sent home once a week\_\_\_\_\_

The school offered to set up home schooling \_\_\_\_\_

The school counselor/psychologist offered to meet with you \_\_\_\_\_

    1 time\_\_

    Once a month\_\_\_\_\_

    Once a month throughout the school year\_\_\_\_\_

    Other \_\_\_\_\_

The school encouraged classmates to keep in touch with your child\_\_\_\_\_



Once a week \_\_\_\_

Other \_\_\_\_

On a scale from 1 to 5, please circle the number which applies to your feelings of support by the following people at the time of diagnosis and during your child's treatment. How would you rate:

1. Your child's classroom teacher or homeroom teacher?

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

If your child is in middle school or high school, please rate the teacher of each subject.

Subject: English

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: Math

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: Science

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: History

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

Subject: P.E.

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unresponsive	Unresponsive	Neutral	Supportive	Very Supportive	Not Applicable

Subject or Other: \_\_\_\_\_

1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The classroom aide?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school principal?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school counselor?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The school psychologist?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The vice-principal or dean?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The child's coach for a sport?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The Special Education teacher?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable

Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable
The speech/language teacher?					
1	2	3	4	5	N/A
not supportive	somewhat supportive	average support	very supportive	extraordinary support	Not Applicable
Very unsupportive	Unsupportive	Neutral	Supportive	Very Supportive	Not Applicable

## Parent Interview

Male\_\_ Age\_\_

Female\_\_ Age\_\_

### Your Family

1. What was each of your initial reactions to your child's diagnosis of cancer?
2. What was your child's initial reaction to his/her diagnosis of cancer?
3. How have you each experienced having a child with cancer?
4. What have you each done to help you cope with this experience?
5. Did the diagnosis affect your marital relationship?  
If you were not married, did the diagnosis affect your relationship with a significant other who was not the child's parent?  
If yes to any of these questions, the parents will be asked how the relationship was affected.
6. Prior to your child's diagnosis, what were events that you were looking forward to?  
What kinds of issues were of concern?
7. Did the diagnosis affect your familial relationships as a whole? If yes, how?
8. What, if any, concerns do you have for your child's future health issues?  
Is there anything I have not asked you about your family that you would like to add?

### Childhood Cancer and the School

1. How did you experience your child's return to school after treatment began?
2. What school personnel showed you the most support?  
How did they show this support?
  - a. Did the school provide counseling services for you or refer you for other services?
  - b. Did the school or hospital inform you about services available for your child according to Special Education law?  
If not, were you able to receive parent education about services available to you?  
What resources did you use? .
3. How did the school and hospital personnel collaborate?
4. What school personnel showed you the least support?  
Why do you feel this way?  
What do you wish they had done?
5. How did your child's teacher react to your child's illness?
6. What did various school personnel do to show support for your child?
7. What knowledge did school personnel display about how cancer and its treatment can affect learning? Please describe this.
8. How did other children at your child's school react to his/her cancer diagnosis and treatment?
9. Did the diagnosis and treatment affect your child's social relationships at school?  
If parents say yes, they will be asked to describe what happened.
10. How did your child do academically when he/she returned to school?
11. Did you notice any changes in the behavior of your child's siblings at school?  
If so, what did these changes look like?
12. How did your child's siblings do academically through this ordeal?
13. What did the school(s) do for your child's siblings?  
Is there anything that I have not asked you about your family's experience with the school that you would like to add?

### Child Questionnaire

These questions are a guideline for the interview with the child. Basic questions will be asked, but the investigator will follow-up on what the child feels is important to express. Since the children in this study are adolescents, developmentally, it is important that they feel they are in charge of the interview rather than the investigator. This is especially important because they have lost so much of their autonomy due to their illness.

1. How did you feel when you found out you had cancer?
2. What was the first thing that came to mind?  
What were your thoughts three months after the diagnosis?
3. What was it like to have treatment? Did you have any side effects?
4. How did you feel when you experienced the side effects?
5. How do you feel about yourself since your diagnosis and treatment?
6. How did you feel around people as you continued treatment?
7. As a teenager, how has your diagnosis affected your relationship with your parents?
8. What was it like returning to school once you knew you had cancer?  
Was there a difference once you started or ended treatment?
9. Do you feel like your treatment has affected your school performance in any way?  
If so, how?
10. Did your friends understand what having cancer meant? If so, what did they think?  
If not, what did they think?  
How has having treatment affected your social life?
11. Is there anything you would like to add about your experience?

Teacher Survey

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
mm dd yy

A. About This Student's School Program

A1. What was the first date on which this student attended your school this school year? (This would be the first day of the school year if this student has attended your school all year, or the first day s/he moved to the school if s/he began attending it mid-year.) PLEASE ENTER DATE.

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
mm dd yy

A2. What is the current grade level placement of this student? \_\_\_\_\_

A3. Does this student participate in any of the following? PLEASE CIRCLE ALL THAT APPLY.

1. Program for gifted and talented students
2. Special Education
3. Chapter 1
4. Summer school during the previous summer
5. Free/reduced price lunch program
6. None of these

A4a. Has this student made any of the following transitions within the past 9 months? PLEASE CIRCLE ONE NUMBER.

- 1 Elementary to middle school.
- 2 Middle school to high school PLEASE CONTINUE WITH A4b
- 3 No transitions this past year PLEASE GO TO QUESTION A5a

A4b. Which of the following were provided to support this student's transition? PLEASE CIRCLE ALL THAT APPLY.

1. Staff or students from your school visited the sending school to meet with groups of students who were preparing for the transition.
2. Groups of transitioning students visited your school before school started.
3. Information was provided to your school staff by the sending school about this student (e.g., student performance information ,disability awareness).
4. Your school staff met with staff of the sending school specifically about this student.
5. Parent and/or student met with staff of this school before starting school here.
6. Preparatory strategies were developed specifically for this student (e.g., behavior plans, school scheduling modifications, etc.)
- 7 Other: \_\_\_\_\_
8. None of these
9. Don't know

A4c. How would you rate the amount of planning and support that was provided this student during this transition? PLEASE CIRCLE ONE NUMBER.

1. It was more than he/she needed.
2. It was appropriate to the needs of this student.
3. This student could have benefited from more transition support.
4. Don't know

A5a. Does this student currently have either an Individualized Education Plan (IEP) for special education or related services (which might include monitoring by special education staff) or a “504 plan” for students with cancer? PLEASE CIRCLE ONE NUMBER

1. Yes, this student has an IEP for special education services
2. Yes, this student has a 504 plan
3. No

A5b. Who participated in the most recent IEP or 504 plan development or review for this student? PLEASE CIRCLE ALL THAT APPLY.

1. General education academic subject teacher(s)
2. General education vocational teacher(s)
3. Special education teacher(s)
4. School administrator (e.g., principal, special education director)
5. School counselor or psychologist
6. Related services personnel (e.g., speech therapist/pathologist, occupational therapist).
7. Parent/guardians
8. Student
9. Staff of outside service agency Please specify type of staff: \_\_\_\_\_
10. Outside consultant Please specify type of consultant \_\_\_\_\_
11. Employer
12. Representative from postsecondary institution
13. Advocate
14. Other Please specify: \_\_\_\_\_

C. About This Student’s Performance and Family Support

C1a. To the best of your knowledge, during this school year, about how many days was this student absent due to his/her illness?

- \_\_\_\_\_ Number of days  
\_\_\_\_\_ Don’t know

C2. Approximately how often have you communicated with this student’s parent/guardian(s) during this school year about this student’s progress (by phone, in person, or in writing)?

PLEASE CIRCLE ONE NUMBER.

- 0 Never
- 1 Once
- 2 A few times over the school year
- 3 Once every other month
- 4 Once a month
- 5 Once a week or several times a month
- 6 Every day or several times a week

C3. How involved is this student’s parent/guardian(s) in his/her school experiences (e.g., monitoring homework, student’s progress in school, advocating for school services)?

PLEASE CIRCLE ONE NUMBER.

- 1 Not at all involved
- 2 Not very involved
- 3 Fairly involved
- 4 Very involved
- 0 Don’t know

C4. Which services did your school offer to parents or students with cancer? Please circle all that apply.

1. Visits with the school counselor.
2. Testing by the school psychologist
3. Referral to County Mental Health Services
4. Meetings with parents, the student's teachers and the school counselor and/or an administrator
5. Meetings with the student with cancer, the parents, the student's teachers, and the school counselor and/or an administrator
6. Homework packets provided for the parent for pick-up or provided on-line
7. Home teacher provided by the school
8. Other \_\_\_\_\_

C5. What number of parents with children with cancer requested any of the services offered above for themselves? None\_\_\_ Number\_\_\_

Name the services from those listed above \_\_\_\_\_

For their children? None\_\_\_ Number\_\_\_

Name the services from those listed above \_\_\_\_\_

D. About You

D1. In what capacity(ies) are you involved with this student? PLEASE CIRCLE ALL THAT APPLY.

1. Provide instruction directly to this student
2. Provide related services directly to this student
3. Provide consultation services to student's teacher(s)
4. Provide case-management (i.e., program monitoring) for this student
5. Program administrator
6. Other: \_\_\_\_\_

D2. Approximately how often do you currently have contact with this student? PLEASE CIRCLE ONE NUMBER.

1. Daily
2. 2 to 3 times per week.
3. Once a week
4. Less than once per week
5. Once per month
6. Once every two to six months PLEASE GO TO QUESTION D3
7. Very rarely

D2a. How much time do you currently have contact with this student each day in a typical week?

PLEASE WRITE ONE NUMBER IN EACH BOX. IF YOU DO NOT SEE THIS STUDENT ON A PARTICULAR DAY, PLEASE WRITE IN "0".

Minutes or Hours      Monday      Tuesday      Wednesday      Thursday      Friday

D3. What is the highest level of education you have completed? PLEASE CIRCLE ONE NUMBER.

- 1 Bachelor's degree
- 2 At least 1 year of course work beyond a bachelor's but not a graduate degree



- 3 Master's degree
- 4 Education specialist or professional diploma with at least 1 year of course work past a master's degree
- 5 Doctorate degree
- 6 Other (please specify)

D4. Which of the following certificates, credentials, or licenses do you hold in this state? PLEASE CIRCLE ALL THAT APPLY.

- 1 General education credential
- 2 Disability-specific credential or endorsement
- 3 Special education credential or endorsement (for more than one disability category)
- 4 Speech/language certification
- 5 Physical therapy license
- 6 Occupational therapy license
- 7 Other: \_\_\_\_\_
- 8 None of these

D5. Which best describes you? PLEASE CIRCLE ALL THAT APPLY.

- 1 African-American or Black
- 2 American Indian or Alaskan Native
- 3 Asian
- 4 Caucasian or white
- 5 Hispanic, Latino, or other Spanish origin
- 6 Native Hawaiian
- 7 Other Pacific Islander
- 8 Other: \_\_\_\_\_

D6. What is your main role in this school? PLEASE CIRCLE ALL THAT APPLY.

- 1 General education classroom teacher PLEASE CONTINUE WITH QUESTION D7
- 2 Special education classroom teacher PLEASE CONTINUE WITH QUESTION D7
- 3 Resource room teacher PLEASE CONTINUE WITH QUESTION D7
- 4 Related services provider (e.g., speech therapist)
- 5 Program specialist (e.g., full inclusion specialist)
- 6 Case manager
- 7 School psychologist
- 8 School counselor
- 9 Other: \_\_\_\_\_

THE REMAINING QUESTIONS IN THIS SECTION ARE FOR CLASSROOM TEACHERS. IF YOU ARE NOT A TEACHER, PLEASE GO TO QUESTION D11.

D7 How many years have you been a teacher?

\_\_\_\_\_ Years in teaching

D8. How many years have you had special education students in your classroom?

\_\_\_\_\_ Years in teaching special education students

D9. Which of the following best describes your current teaching job? PLEASE CIRCLE ONE NUMBER.

- 1 Full-time teacher

- 2 Part-time teacher
- 3 Itinerant teacher (i.e., you provide instruction at more than one school)
- 4 Long-term substitute (i.e., fills the role of a regular teacher on a long-term basis, but still considered a substitute)
- 5 Other: \_\_\_\_\_

D10. Which of the following types of credentials do you hold in this state for your current teaching job? PLEASE CIRCLE ONE NUMBER.

- 1 Regular or standard or advanced certificate
- 2 Probationary certificate
- 3 Provisional (or other type given to persons who are still participating in an “alternative certification program”)
- 4 Temporary certificate (requires some additional coursework and/or student teaching)
- 5 Emergency certificate or waiver
- 6 Other: \_\_\_\_\_

D11. During the past 3 years, have you had in-service training to help you do the following? PLEASE CIRCLE ALL THAT APPLY.

- 1. Work with students with chronic illness.
- 2. Work with students who have cancer
- 3. Work with students with disabilities.
- 4. Work with students “at risk”
- 5. None of these

D12. How would you rate your current ability to work with student with cancer? PLEASE CIRCLE ONE NUMBER ON EACH LINE.

1-Very good 2- Good 3-Adequate 4- Limited

D13. Please indicate the extent to which you agree or disagree with each of the following statements. PLEASE CIRCLE ONE NUMBER ON EACH LINE.

- 1. Strongly Agree
  - 2. Agree
  - 3. Disagree
  - 4. Strongly Disagree
  - 5. Not Applicable
- a. At this school, I am given the support I need to teach students with cancer 1 2 3 4 5
- b. I feel comfortable working with students with cancer. 1 2 3 4 5

Please add any thoughts below regarding your experience working with students with cancer.

Thank you for your participation!

Please return this survey in the stamped, addressed envelope provided.

Please go to the next page to find out about your appreciation gift.

Dear Teacher,

Thank you for your help! I would like to express my appreciation to you for taking the time to complete this survey by sending you your choice of a Starbucks, Peete's, or Jamba Juice gift card. To whom should I send the gift card, and what type would you like?

Name: \_\_\_\_\_

Street address: \_\_\_\_\_

City/state/zip code: \_\_\_\_\_

Gift card choice \_\_\_\_\_

Please return this letter in the enclosed stamped, addressed envelope to me.

This must be sent separately from the survey.

Thank you again.

Sincerely,

Shelley Nielsen

Principal Survey

A. School and Community Characteristics

A1. Which of the following best describes your school? PLEASE CIRCLE ONE NUMBER.

- 1 A regular elementary or secondary school that serves a wide variety of students
- 2 School that serves only students with disabilities
- 3 School that specializes in a particular subject area or theme, sometimes called a magnet school
- 4 Vocational-technical school
- 5 Alternative school
- 6 Charter school
- 7 Juvenile justice facility
- 8 Another kind of school (please describe):

A2. Which of the following describes this school? PLEASE CIRCLE ALL THAT APPLY.

- 1 Public school
- 2 Private school
- 3 Residential/boarding school

A3. What grade levels are taught at this school? \_\_\_\_\_

A4. Currently, about how many students are enrolled at your school?  
\_\_\_\_\_ Number of students enrolled

A5. How many students do you have in school who have been or are being treated for cancer?  
\_\_\_\_\_

A5. Which of the following best describes the community in which this school is located?  
PLEASE CIRCLE ONE NUMBER.

- 1 Rural community
- 2 Small city or town
- 3 A medium-sized city
- 4 A suburb of a medium-sized city
- 5 A large city
- 6 A suburb of a large city
- 7 A very large city

Other \_\_\_\_\_

B. Student Characteristics

B1. How many students are currently being treated for cancer? \_\_\_\_\_  
Please indicate specifically if they have an IEP or a 504 Plan

\_\_\_\_\_  
\_\_\_\_\_

B2. Which students with cancer are from these socioeconomic levels?

- 1. Upper Number of students \_\_\_\_\_
- 2. Upper middle class Number of students \_\_\_\_\_
- 3. Middle class Number of students \_\_\_\_\_
- 4. Low Income Number of students \_\_\_\_\_

B3. In the (Date of school year depends upon when child was diagnosed and/or returned to school) school year, what number of students with cancer who were enrolled at the beginning of the year left school permanently prior to the end of the school year.

\_\_\_\_\_ Number of students who moved

C. Staff, Programs, and Resources

- C1. Which services did your school offer to parents or students with cancer? Please circle all that apply.
1. Visits with the school counselor.
  2. Testing by the school psychologist
  3. Referral to County Mental Health Services
  4. Meetings with parents, the student's teachers and the school counselor and/or an administrator
  5. Meetings with the student with cancer, the parents, the student's teachers, and the school counselor and/or an administrator
  6. Homework packets provided for the parent for pick-up or provided on-line
  7. Home teacher provided by the school
  8. Other \_\_\_\_\_
- C2. What number of parents with children with cancer requested any of the services offered above for themselves? None\_\_\_ Number\_\_\_\_  
 Name the services from those listed above \_\_\_\_\_  
 For their children? None\_\_\_ Number\_\_\_\_  
 Name the services from those listed above\_\_\_\_\_
- C3. What percentage of your teachers have had training in working with children and families with cancer?\_\_\_\_\_
- D. Special Education Policies and Practices
- D1. How many students does your school have in Special Education, including students with 504 Plans? \_\_\_\_\_
- D2. Does your school have full inclusion?\_\_\_\_\_
- If not, please check off the Special Education classes you have:
- |                        |                          |
|------------------------|--------------------------|
| Special Day Class_____ | Number of students _____ |
| Resource Classes_____  | Number of students _____ |
- D3. Which of the following placement options does your school have for cancer students with special education needs? PLEASE CIRCLE ALL THAT APPLY.
- 1 General education
  - 2 Part-time resource room for special education students
  - 3 Self-contained special education classrooms
  - 4 Other : \_\_\_\_\_
- D4. Do you have a formal and systematic written procedure for providing special education services for students who have been or are being treated for cancer?
1. Yes
  2. No
- D4a. Which of the following are involved in this procedure? PLEASE CIRCLE ALL THAT APPLY.
- 1 School team conference (e.g., multidisciplinary team)
  - 2 Individual consultation provided to teachers by a specialist
  - 3 Special education team
  - 4 Other:\_\_\_\_\_
- D5. Which of the following are available to general education teachers when students with cancer with accommodations are included in their classes? PLEASE CIRCLE ALL THAT APPLY.
- 1 Consultation by special education staff or other staff

- 2 Special materials to use with the students
- 3 Inservice training on the needs of the students
- 4 Teacher aides, instructional assistants, or aides for individual students
- 5 Smaller student load or class size
- 6 Other: \_\_\_\_\_
- 7 None of these

D6. When a student has cancer, is he/she required to take mandated standardized tests?

Yes \_\_\_ No \_\_\_

If so, what accommodations have been made:

None were needed \_\_\_\_\_

More time was given \_\_\_\_\_

A teacher brought the test to the student at home \_\_\_\_\_

A teacher brought the test to the student in the hospital \_\_\_\_\_

Other \_\_\_\_\_

Thank you for taking part in this survey. Please return the survey in the enclosed addressed, stamped envelope.

Please go to the next page to select your thank-you gift.

Dear Principal,

I appreciate your time in filling out this survey. When I receive this survey, you will be sent a gift card to your choice of the following: Starbucks, Peete's, Jamba Juice or another place of your choosing.

Please advise me if you would like this sent to you at your school, or at another address of your choosing:

Name \_\_\_\_\_

Street Address \_\_\_\_\_

City, State, Zip Code \_\_\_\_\_

Gift Card Choice \_\_\_\_\_

Please send this letter to me in the addressed, stamped envelope provided, separate from the survey.

Thank you,

Shelley Nielsen

# Appendix C



Outside Reader 1  
Observations upon Reading of Dissertation of Shelley Nielsen  
Attorney

I have read the dissertation by Shelley Nielsen with great interest. I found her research and conclusions to bear out many assumptions I had about this subject, and also noted a few surprising findings.

As I am trained as an attorney, and have had fifteen years of courtroom experience both as a prosecutor and a commissioner (judicial officer conducting trials and hearings), I am very familiar with the idea of eliciting information by questions posed to witnesses, or subjects in this case. I was struck, though, by the method of questioning used by the interviewer here, due to the suggestive nature of the questions and responses. These empathic responses and genuine caring that the interviewer demonstrated were appropriate to the focus of the interviews, given the sensitive nature of the subject matter. While I understand that there is a fundamental difference between legal questioning and the more personal interviewing technique used here, I could not help but wonder whether the subjective stance of the interviewer had any suggestive effect on the answers given by the families.

The research done by Ms. Nielsen was obviously extensive, and it is clear that she has a firm grasp on her subject. I was unfamiliar with the type of study that is based on discovering information, rather than that of trying to empirically prove or disprove something. Therefore, I found the methodology very interesting, especially the different measurement scales used in analyzing the interviews, and organizing the information presented. The tables were very clear, and gave a good overview of the data collected.

In addition, the tables accurately portrayed the information from which Ms. Nielsen drew her conclusions. They were constructed in a simple and straightforward fashion, and were reflective of the content from the interviews and questionnaires.

The answers given by the families in the questionnaires required the subject to rate the responsiveness of individuals. One problem with self-reporting of satisfaction with various school personnel, and not accounted for in this study, is the effect of the positive or negative regard a subject may generally have as a personality trait. One person's "4" could be another person's "2" with the exact same set of circumstances. This variance could be dependent on the outlook the subject generally has about the fulfillment of expectations, and the general outlook one has. I am wondering if there is a way to account for this type of variance in studies of this type so as to neutralize this factor.

The interview excerpts used to illustrate the various perspectives of the subjects were very helpful, and really put a human face on these families. Many situations were very sad, of course, and most especially those families that were burdened by multiple problems in addition to having a child with cancer. The functionality of most of the families in the face of a devastating health crisis was remarkable, though, especially the observation that most families with pre-existing marital disharmony were drawn together during the crisis. Also surprising to me was the relative lack of self-consciousness that the children had about their appearance as a result of their treatment.

Unfortunately, I was not surprised that the schools had such uneven responses to the cancer of their students. It seemed to me that most families were at the mercy of the idiosyncrasies of the educational institution they were involved with. While some of the schools had personnel who acted with a lack of compassion, and at times even cruelly, many school personnel were very kind. Yet most of schools seemed to have idiosyncratic internal

bureaucracies that were unprepared to deal with a child with a serious, yet non-contagious illness. Ms. Nielsen's study shows how much a protocol dealing with these issues is needed for schools and their staff, so that these children and families need not deal with yet one more difficulty. It would also help school personnel to understand the needs of the child and the family, and have a plan to deal with this type of contingency.

I hope that this study will spur further research in this area, with the hope that a protocol could ultimately be developed and utilized by school districts to educate those individuals on the best way to deal with a student who has cancer, and to maximize resources for the family. Ms. Nielsen's study contributes an important piece of research to what I hope will be a realized aspiration one day.

Outside Reader 2  
MA-CCC Speech

I have read the dissertation by Shelley Nielsen, and found it to be thorough and well-organized. Although the study was very ambitious with a tremendous amount of data, it was managed using the two models, Bronfenbrenner's and the Double ABCDX model. These models gave the paper structure and organized it along research lines which made it not simple, but relatively straightforward to read and grasp. There was satisfying flow of data about the families as they experienced cancer from within the family, to hospital, to school, with a summary of each.

In addition, the data was triangulated with interviews, questionnaires, and surveys, and supported by research. In the interviews, Shelley demonstrated the ability to elicit candid responses from her participants, and used quotes from these interviews to back up her summaries and conclusions. As a speech and language pathologist, I appreciated the skill it took to ask the right questions, and to demonstrate both the verbal and nonverbal ability to draw out the families' feelings and thoughts. These interviews made the paper interesting to read and gave the reader a sense of the difficulty the participants had experienced.

To this reader, the tables are not as readily revealing about the survey and questionnaire data as might be hoped. The sheer volume of information precludes themes being easily derived from this body of data. Although the discrepancies shown between the answers given in interviews and the responses shown on surveys/questionnaires were potentially threatening to the credulity of the study, the issue was addressed satisfactorily by the researcher, who offered possible explanations for these disparities. She recognized that there appears to be a natural difference between the responsive behavior of humans in the personal interview situation versus written questionnaires. The creation of more useful surveys and questionnaires might have helped the triangulation.

Most importantly, however, Shelley's study was edifying and socially and educationally important. It attempted to clarify the relationships among the social systems surrounding children with severe chronic illness, and to draw some attention to areas of weakness, injustice, and even illegality within the system. The recommendations for further study and for improvement in the system were valuable and important parts of the research. Overall, I am more than pleased to have had the opportunity to read and critique this important study, and impressed with the persistence and high standards of the researcher.

Outside Reader 3  
MA in Organizational Psychology

I found this to be really interesting research, something I didn't think about much being a student who has coped in the classroom.

This got me asking myself the following questions:

- What is the rate of children with cancer in schools, from past to present?
- How do other diseases/chronic illnesses compare in terms of length and treatment?
- Where does the accountability lie? On the teachers? Principals? School district? State? Fed government?

I thought that having the schools participate in the support and guidance of these children was a high quality problem (a bonus to have but not a must) BEFORE I read that children rely on the schools for their only source of normalcy while going through treatment/remission.

Implications:

I am shocked to infer that teachers do not have special education courses as part of their degree programs!

I am also shocked to infer that the school system has not updated their Health Education courses to include chronic illnesses (as a result of stress, etc).

I came to the conclusion as well that there is a need for change within the school system that calls for the need for further research regarding school policy and curriculum in regards to how they are handling the growing incidence of childhood cancer and with chronic illness in general. I think Ms. Nielsen's suggestion for studies to be done on training simulation effects would help the cause greatly, driving a need for change at the policy level.

I am surprised that the researcher did not suggest social action in terms of developing NFP/NGO organizations to raise money to work with the school administration at the state and/or federal level on this topic.

Overall, I found this VERY interesting and compelling research, a topic that seems is overlooked and not well researched. I could tell that the researcher has a passion for childhood education and advocacy. It showed in the quality of her work.

# Appendix D

Table 1  
Parent Demographics

Family	Income	Ethnicity	Education	Occupation	Insurance	Not Covered
1-M	\$25,000-50,000	White	M: HS, some college F: AA degree	M:Family Centered Care at hospital; F: Produce Manager	Yes	\$400-\$500
2-S	0-\$25000	Pacific Islander	S*:BA	Nurse	Yes	Home health supplies
3-M	\$110,000 to \$150,000	Asian-Chinese	F-Masters in Engineering	Engineer	Yes	<1%
4-M	\$150,000 and up	White	M- Masters in Computer Science	Software Engineer	Yes	Infusions at home
5-D, living With MSO	Laura: \$25000-\$5000 Larry-MSO-\$75000-\$111000 Matt: \$50,000-\$75,000	White	M:BA MSO: HS F: DDS	M:Preschool Teacher of children with Autism MSO: Telecommunications Tech F: Dentist	Yes	M:0 MSO:0 F:\$7500
6-D	\$25000-\$50000	White and Native American	M :High school	M:Caretaker	Yes	Acquired additional health insurance for rest of expenses
7-M	\$150,000-up	White	M:BA F:MSEE	M-homemaker F-Engineering Manager.	Yes	\$3000

8-M	\$110,000- \$150000	White	M:BA, teaching credential F: BA	M:sales F:teacher	Yes	\$10,000
9- RM	\$50000- \$75000	White	M:HS SF:AA	M:Admin assistant for county SF: At Home healthcare worker	Yes	\$50000 over 8 years
10- M	\$25000- \$50000	Black	M-AA F-Post Graduate	M-LVN F: health Analyst	Yes	
11- D	0-\$25000	Latino	M:Did not say	Cashier	Yes-covered in full	
12- RM	\$150.000- up	white	M:some college SF:BA	M:homemaker SF:Corporate Marketing VP	Yes	deductible
13- M	\$25000- \$50000	Black	M:BA	M: Nurse	No-All covered by health services	
14- M	DK	White	M:BA	M:homemaker	Yes	
15- M	\$50000	Black	M:Not answer F:HS	M:homemaker F:airline mechanic	Yes	\$8,000 not covered
16- D	M: \$25000- \$50000 F:\$50,000- \$75000	Latino	M:HS F:10 years of school	M:CAN F:truck driver	F:health insurance	20%
17- M	\$110,000- \$150,000	White	M:BA F:MA	M: homemaker F: Accountant	Yes	20%

S= sister to child MSO=mother's male significant other  
SF=stepfather D=divorced  
M=married RM-remarried

Table 2  
Children with Cancer

COF	Gen.	CA	LS	NOS	Age at Dx	TOC	LOT	TOS	SP
1	F	18	both parents	3	11	Leukemia	7 years	Public	N/A
2	M	15	father and siblings	3	12	Leukemia	6 months	Public	N/A
3	F	20	Father, stepmother, siblings, stepsibling	2 brothers, 1 sb#, 1 ss##	14	Leukemia	Ongoing	Public	Speech Therapy, IEP-reading disorder
4	F	19	Both parents	0	16	Non-Hodgkins Lymphoma	2 years-still having partial treatments	Public	N/A
5	M	13	Mother, MMSO**, Visits Father 1-3 times month	1	11	Osteosarcoma	1 year ; Surgeries ongoing	Public	N/A
6	M	16	Mother and brothers	2	15	Burkett's Lymphoma	4 months	Public	N/A
7	F	19	Parents	1	17	Non-Hodgkins Lymphoma	18 months; Ongoing	Public	N/A
8	M	21	Parents	1	16	Leukemia	5 years	Public	SpEd DS***
9	F	17	Divorced Parents	3	9	Leukemia and Lymphoma	2 years-Ongoing	Public	N/A
10	M	13	Parents	2	13	Leukemia	3 months so far-ongoing	Public	SpEd
11	M	16	Parents; Now mother	3	14	Leukemia	2 years-still ongoing	Public	N/A



12	M	13	Mother and sf	1	13	Ewing Scarcoma	8 months Ongoing	Private	N/A
13	F	17	Parents	6	16	Autoimmune hepatitis	3 months-Ongoing	Public	N/A
14	M	12	Parents	2	8	Leukemia	3.5 years	Private	IEP
15	M	19	Parents	1	15	Hepa-Cellular Carcinoma	4 years-ongoing	Private	504, IEP
16	M	21	Shared custody	1	16	Hodgkins	3 months	Public	N/A
17	F	16	Parents	2	15	Hodgkins	6 months	Public	504 Plan

Each child is the same ethnicity as their parents.  
The child of each family is according to number.

Example:

C1 is the child of F1

\* At time of diagnosis

\*\*MMSO-mother's male significant other

\*\*\*DS-Down Syndrome

+ -Type of school at time of diagnosis

sb#-stepbrother

ss##-stepsister

Legend:

COF – Child of Family

GEN – Gender

CA – Current Age

LS – Living Situation

NOS – Number of Siblings

TOC – Type of Cancer

LOT – Length of Treatment

TOS – Type of School

SP – Special Program

Table 3  
Likert Scale: Parent Ratings of School Personnel  
Mothers' Responses

1=not supportive, 2-somewhat supportive, 3-average support, 4-very supportive,  
5-extraordinary support, N/A-not applicable

Family	1	2*+	3*	4	5	6	7	8	9	10	11	12	13	14++	15	16	17
School Personnel																	
Homeroom	5	2	-	n/a	4	1	-	n/a	2	5	4	5	4	n/a	1	4	5
English	5	2	-	5	1	1	5	n/a	1	4	4	5	4	n/a	3	4	5
Math	5	2	-	5	4	1	3	n/a	1	4	4	4	2	n/a	2	4	3
Science	n/a	1	-	5	5	1	3	n/a	1	4	4	5	5	n/a	2	4	5
History	n/a	1	-	5	1	1	4	n/a	1	4	4	5	5	n/a	2	4	5
P.E.	n/a	4	-	n/a	4	2	n/a	n/a	n/a	4	4	n/a	5	n/a	n/a	5	1
Classroom Aide	n/a	5	-	n/a	n/a	n/a	n/a	5	1	4	4	n/a	4	n/a	2	4	n/a
Principal	1	n/a#	-	++	+++ n/a	1	3	1	1	5	5	5	4	n/a	3	4	2
Counselor	5	5	-	n/a	5	4	3	1	1	5	4	n/a	4	n/a	3	5	2
Psychologist	2	n/a	-	n/a	n/a	n/a	-	1	n/a	4	5	n/a	4	n/a	n/a	5	4
Vice Principal/Dean	1	n/a	-	4	4	n/a	4	1	1	4	5	5	4	n/a	n/a	4	n/a
Sport Coach	5	n/a	-	n/a	n/a	n/a	n/a	1	na	4	4	n/a	4	n/a	n/a	n/a	n/a
Special Education	n/a	n/a	-	n/a	n/a	n/a	n/a	5	na	4	4	n/a	3	n/a	5	n/a	5
Speech/Language	n/a	n/a	-	n/a	n/a	n/a	4	1	na	4	4	n/a	3	n/a	n/a	n/a	n/a
Other																	
Nurse	-	-	-	-	-	-	-	-	-	-	-	-	5	n/a	-	-	-
Technology Skills	-	-	-	-	4	-	-	-	-	-	-	-	-	n/a	-	-	-
Attendance	-	-	-	-	-	2**	-	-	-	-	-	-	-	n/a	-	-	-
Religion	-	-	-	-	-	-	-	-	-	-	-	5	-	n/a	-	--	-

\*Stepmother did not fill out survey \*+ Older Sister filled out survey #Sister said she never spoke -to the principal or vice principal ++did not rate; just said principal did not interact with the family +++ rated N/A, but also said family never talked to principal. \*\*kept calling

Table 4  
Likert Scale: Parent Ratings of School Personnel  
Fathers' Responses

	1	2	3	4+	5	5	6*	7	8	9	10	*11	12	*13	*14	15	16+	F17*
Family		**			***			+++										
School Personnel																		
Homeroom	5	-	5	-	n/a	4	-	n/a	n/a	n/a	4	-	4	-	-	1	DK	-
English	5	-	4	-	n/a	1	-	n/a	n/a	2	5	-	4	-	-	1	DK	-
Math	5	-	4	-	4	3	-	n/a	n/a	2	4	-	4	-	-	1	DK	-
Science	n/a	-	n/a	-	5	4	-	n/a	n/a	2	4	-	4	-	-	1	DK	-
History	n/a	-	4	-	4	3	-	n/a	n/a	2	4	-	4	-	-	1	DK	-
P.E.	n/a	-	n/a	-	n/a	n/a	-	n/a	n/a	n/a	5	-	4	-	-	1	DK	-
Class Aide	n/a	-	3	-	n/a	n/a	-	n/a	5	n/a	4	-	n/a	-	-	n/a	DK	-
Principal	5	-	3	-	n/a	2	-	5	1	1	4	-	5	-	-	1	DK	-
Counselor	n/a	-	3	-	5#	3	-	4	1	1	4	-	n/a	-	-	1	DK	-
Psychologist	n/a	-	n/a	-	n/a	++	-	n/a	1	1	4	-	n/a	-	-	1	DK	-
Vice Principal	5	-	3	-	4	++	-	5	1	1	5	-	5	-	-	1	DK	-
Sport Coach	5	-	n/a	-	n/a	N/A	-	n/a	4	n/a	5	-	5	-	-	n/a	DK	-
Special Educ.	n/a	-	n/a	-	n/a	++	-	n/a	5	n/a	5	-	n/a	-	-	4	DK	-
Speech/Lang	n/a	-	n/a	-	n/a	++	-	n/a	1	-	5	-	4	-	-	1	DK	-
Other																		
Art	n/a	-	5	-	n/a	-	-	n/a	-	n/a	-	-	-	-	-	-	-	-
Nurse	n/a	-	5	-	-	-	-	n/a	-	-	-	-	-	-	-	-	-	-
Technology	n/a	-	n/a	-	n/a	++	-	n/a	-	-	-	-	-	-	-	-	-	-
Attendance	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Religion	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Spanish	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1	-	-

1=not supportive    2=somewhat supportive    3=average support    4=very supportive

5=extraordinary support    n/a= not applicable

\*\*Father did not fill out survey

\*\*\*-Male Significant Other

#Always felt was nice to him (father)

+Father had no knowledge of the school relationship. DK-Does not know

+-said had no contact

+++-"My wife took care of the majority of the school communication, without my involvement. Since I have limited knowledge, I will indicate N/A."

SF-Stepfather

Table 5  
 Parent Perceptions in Interviews  
 of  
 Most Supportive School Personnel  
 Mothers

Families	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
School Personnel																	
Elementary Teacher														x*			
6 <sup>th</sup> grade Teacher		x												x#			
Homeroom	x																
English	x						x										x
Math	x																x
Science																	
History														x			
P.E.	x																
Class Aide								x									
Principal											x	x	x				
Counselor	x	x			x	x	x										x
Advisor						x											
Psychologist																	
Vice Principal/Dean							x				x		x				
Sports Coach								x									
Special Ed.									x							x	
Speech/Lang																	
Teachers on the Whole-Middle School													x				
Teachers as Whole H.S.				x							x		x				x
Other																	
Art																	
Nurse	x			x					x				x				
Technology																	
Attendance				x													x
Religion														x			
Spanish							x										

\*This was his teacher when he was first diagnosed. The sixth grade teacher is his current teacher. He is still being followed up medically.  
 + This is the principal in the middle school.

Table 6  
 Parent Perceptions in Interviews  
 of  
 Least Supportive School Personnel  
 Mother

School Personnel	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Homeroom																	
English																	
Math													x				
Science		x															
History																	
P.E.																	
Class Aide																	
Principal	x	x						x	x					x*			
Counselor							x		x								
Psychologist									x								
Vice Principal		x							x								
Sport Coach																	
Special Ed																	
Speech/Lang																	
Teachers as a Whole MS		x			x												
Teacher on Whole HS						x			x						x		x
Other																	
Art																	
Nurse																	
Technology																	
Attendance					x	x			x						x		
Religion																	
Spanish													x				
Families																	

\* Her son was diagnosed in 2<sup>nd</sup> grade, but just finished treatment this year, 6<sup>th</sup> grade, middle school. He is still being followed medically. The neither principals in elementary school nor middle school were very unsupportive.

Table 7  
 Parent Perceptions in Interviews  
 of  
 Most Supportive School Personnel  
 Fathers  
 Families

School Personnel	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
6 <sup>th</sup> Grade Teacher																	
Homeroom	x																
English	x																
Math	x																
Science																	
History																	
P.E.																	
Class Aide								x									
Principal	x									x							
Counselor																	
Psychologist																	
Vice Principal																	
Sports Coach																	
Special Ed.								x							x		
Speech/Lang																	
Teachers as a Whole MS										x							
Teachers as a Whole HS			x														
Other																	
Art																	
Nurse			x						x								
Technology																	
Attendance			x							x							
Religion																	
Spanish																	

Table 8  
 Parent Perceptions in Interviews  
 of  
 Least Supportive School Personnel  
 Fathers  
 Families

School Personnel	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Homeroom																	
English																	
Math																	
Science																	
History																	
P.E.																	
Class Aide																	
Principal			x					x	x								
Counselor			x						x								
Psychologist									x								
Vice Principal									x								
Sport Coach																	
Special Ed																	
Speech/Lang																	
Teachers as a Whole MS																	
Teachers as a Whole HS									x						x		
Other																	
Art																	
Nurse																	
Technology																	
Attendance								x	x							x	
Religion																	
Spanish																	

Table 9  
 Children's Perception in Interviews  
 of  
 Supportive School Personnel

	1F	3F	6M	7F	8M	9F	11M	12M	14M	16M	17F
F=Female											
M=Male											
Families											
Elementary Teacher											
5 <sup>th</sup> Grade Teacher									x		
6 <sup>th</sup> Grade Teacher											
Homeroom	x		x								
English											x
Math							x				
Science	x										x
History											
P.E.										x	
Class Aide											
Principal							x	x			
Counselor			x								
Advisor											
Psychologist											
Vice Principal/Dean							x				
Sports Coach							x				
Special Education					x						
Speech/Language											
Teachers on the Whole Middle School								x			
Teachers on the Whole High School		x		x						x	
Other											
Art		x									
Nurse							x				
Technology											
Attendance											
Religion											
Spanish											



Table 10  
 Children's Perceptions in Interviews  
 of  
 Least Supportive School Personnel

	1F	3F	6M	7F	8M	9F	11M	12M	14M	16M	17F
F=Female											
M=Male											
Families											
Elementary Teacher											
6 <sup>th</sup> Grade Teacher											
Homeroom											
English						x					
Math											
Science											
History											
P.E.											
Class Aide											
Principal											x
Counselor											x
Advisor											
Psychologist											
Vice Principal/Dean											
Sports Coach			x								
Special Education											
Speech/Language											
Teachers on the Whole Middle School											
Teachers on the Whole High School						x					x
Other											
Art											
Nurse											
Technology											
Attendance			x								
Religion											
Spanish											
Economics		x									

Table 11  
Table of Principal Response

Family Number	Type of School	Type of Community	Grade levels	Number of Students	Number of Students with cancer	Number of Services Offered
1						
2	Public	Medium Size City	Secondary	1116	13	3
3						
4	Public	Suburb of a Large City	Secondary	2520	1	5
5	Public	Small City or Town	Middle	662	1	4
6						
7						
8						
9						
10	Public	Suburb of a Large City	Middle	955	1	2
11						
12	Private/Catholic	Medium Size City	K-8	319	1	4
13	Public	Very Large City	Secondary	2300	3	5
14	Private/Catholic	A Large City	K-8	615	1	5
15						
16	Public	Small City or Town	Secondary	2900	5	6
17	Public	Small City or Town	Secondary	1350	1	3

Principal 1 refers to the principal of Family 1.

If another administrator has responded such as the counselor, then he/she is referred to as Counselor 1. for Family 1.

Table 12  
Principal Survey:  
Special Education Policies and Practices for Children with Cancer

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Family Formal Systematic Written Procedure				x	0					0		0	x	0		x	0
Type of Plan				FEP	0					0		0	IEP	0		x	504
Percentage of Teachers Trained to Work with Students With Cancer				0	10					DK		0	0	50-100		0	0
Assistance Provided to General Education Teachers*				x	x					0		x	x	x		x	x
Student Required to take Mandated State Tests with Accommodations				x	x							0	x	x		x	0

\* Table below describes specific assistance.

Table 13  
Principal Survey:  
Assistance Available to General Education Teachers  
Who Have  
Children with Cancer in their Classrooms

Families:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Consultation by Special Education Staff or Other				x	x							x	x	x		x	x
Special Materials to Use with Students				x	0							x	0	0		x	0
Inservice Training on the Needs of the Students				x	x							0	x	0		x	0
Teacher Aides, Instructional Assistants, or Aides for Individual Students				x	0							0	0	0		x	0
Smaller Student Load or Class Size				0	0							0	0	0		x	0
Other				0	0							0	0	0		0	0

Table 14  
Principal Survey  
Services Provided for Families With a Child With Cancer

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
Visits with school counselor				x	x				x				x	x			x	
Testing by school psychologist																		
Referral to county mental health									x				x				x	
Parent meetings with teachers, school counselor and/or administrator				x	x				x			x	x	x			x	x
Student meetings with parents, teachers, counselor and/or administrator				x					x			x	x	x			x	x
Homework packets provided for pick up or online				x	x				x	x		x	x	x			x	
Home teacher provided				x	x				x	x							x	x
Other																		
Communication and social opportunities with class												x						
Arranged a tutor																	x	

Table 15  
Teacher Demographics

F #	Years Teaching	Level of Ed.	Credential / licensing	Role in School	Years have Taught Sped Students	Contact with student	In-service Training
1	N/A	MA	Counseling-psych	Consult, Case manage, counselor	N/A	Less than once a week	Disability , At-risk
1	34	1 year post BA	Gen Ed	Gen Ed	34	previous	At risk
2	N/A	1 year past MA	Gen ed, Sp/lang, others	Consult, Case manage, counselor.	N/A	2-3x a week	None
3	29	BA	Secondary	Gen Ed art	29	rarely, was daily	none
4	4	MA + 1	Gen. Ed.	Gen Ed	4	Daily	none
5	3	MA	Gen. Ed	Gen. Ed	3	rarely, was daily	At-Risk
6							
7							
8	30	MA	Gen. Ed, Disability Specific, Sp. Ed.	Special Day Class	30	daily	none
9							
10	13	MA +1	Gen & Sped	Special Ed / Case manager	13	1x month	disability, At-risk
11		BA +1	Emergency	Sub/home school		2-3x week	chronic illness, cancer, disability, at-risk
12							
13							
14	5	MA + 1	Standard	General Ed	3	2-3x week	disability, at risk
a							

14	2	BA + 1	General Ed	Gen. Ed	0	daily	disability
b							
14	2	BA	none	PE/Sped	2	1x week	none
c							
15	5	MA	Sped.	Sped./ Program Speciali st	5	daily	disability, at-risk
16		MA	Counselin g	School Counsel or		1x every 2-6 months	N/A
17	27	BA + 1	General Ed	Gen Ed	27	daily	None

F#=Family Number

Table 16  
Knowledge of Cancer  
Teacher Response

Family	I		II	
	Current Ability to Work with a Child with Cancer	Support Given by School	Support Given by School	Comfort Level Working with Child with Cancer
1a	1	1	1	1
1b	2	1	1	2
2	1	1	1	1
3	4	2	2	2
4	1	5	5	5
5	1	2	2	1
6	-	-	-	-
7	-	-	-	-
8	1	4	4	1
9	-	-	-	-
10	2	4	4	1
11	1	2	2	1
12	-	-	-	-
13	-	-	-	-
14 a	3	3	3	2
14b	2	2	2	2
14c	2	2	2	1
15	1	2	2	1
16	2	2	2	2
17	2	2	2	2

I	II
1-Very Good	1-Very Good
2-Agree	2-Good
3-Adequate	3-Disagree
4-Limited	4-Strongly Disagree
	5-Not Applicable



Table 17  
 Teacher Rating of Family Involvement  
 In  
 Child's School Experience

Key:  
 1-Not at all involved  
 2-Not very involved  
 3-Fairly involved  
 4-Very involved  
 0-Don't know

Teacher for Each Family																				
	1a	1b	2	3	4	5	6	7	8	9	10	11	12	13	14a	14b	14c	15	16	17
1																				
2																			x	
3					x						x						x			
4	x	x	x	x		x			x			x				x		x		
0															x					x

Table 18  
 Parent Self-Report of Involvement  
 In  
 Child's School  
 Mothers: Before Diagnosis

Family	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Attendance at:																	
Back-to-School Night	X	x		x	x	x	x	x	x		x			x	x		x
School Program with Child	x			x	x		x	x	x					x			
PTA Meetings									x					x			
School-Site Council														x			
Parent-Teacher Conferences	x				x		x	x	x					x	x		x
Field Trip	x																
Awards		x															
Sports					x												x
Plays					x												
Parent Information Night							x										
Only if Teacher or Principal Called Meeting													x			x	x
Active in:																	
Back-to-School Night	x					x						x		x			
School Programs with Child	x							x						x			
PTA Meetings											x			x			
School-Site Council												x		x			
Parent-Teacher Conference	x							x				x		x			
Classroom Projects	x																
Classroom Volunteer								x				x		x			
Field Trips	x																
Teacher Luncheons							x										
GATE Program							x										
Registration																	
Graduation												x					
School Dinner												x					
Relationship with School																	
None								x		x							
Good	x			x	x				x			x					
Very Good							x										
Contentious														x			

Table 19  
 Parent Self-Report of Participation  
 In  
 Child's School  
 Mothers: After Diagnosis

Family	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Attendance at:																	
Back-to-School Night	x			x			x	x							x		
School Program with Child	x			x						x							
PTA Meetings																	
School-Site Council																	
Parent-Teacher Conferences	x	x		x				x							x		x
Only if Principal or Teacher Called Meeting					x					x			x	x		x	
Field Trip	x																
Graduation				x								x					
On-line Discussion Group							x										
Active in:																	
Back-to-School Night	x							x									
School Programs with Child	x																
PTA Meetings																	
School-Site Council																	
Parent-Teacher Conference	x							x									
Classroom Projects																	
Field Trips																	
Graduation				x													
Registration							x										
Relationship with School																	
None						x		x	x	x							
Good	x			x													
Very Good							x					x					
Difficult																	

Table 20  
 Parent Self-Report of Participation  
 In  
 Child's School  
 Fathers: Before Diagnosis

Family	1	2	3	4	5*	5#	6	7	8	9**	10	11	12**	13	14	15	16	17
Attendance at:										n/a								
Back-to-School Night	x		x		x	x		x	x				x			x		
School Program with Child	x		x		x	x		x	x				x			x		
PTA Meetings																		
School-Site Council											x							
Parent-Teacher Conferences						x		x	x				x			x		
Only If Principal or Teacher Called Meeting											x							
Field Trips	x																	
Concerts					x													
Sports									x				x					
GATE Program	x																	
Active in:										n/a								
Back-to-School Night	x								x				x					
School Programs with Child									x				x					
PTA Meetings																		
School-Site Council																		
Parent-Teacher Conference									x				x					
Classroom																		

Projects																		
Field Trips	x																	
Volunteer in Classroom	x																	
Relationship with School																		
None							x										x	
Good									x									
Very Good							x											

\*-Mother's Significant Other

#-Biological Father

\*\* -Stepfather

Table 21  
 Parent Self-Report of Participation  
 In  
 Child's School  
 Fathers: After Diagnosis

Family	1	2	3	4	5*	5#	6	7	8	9**	10	11	12**	13	14	15	16	17
Attendance at:																		
Back-to-School Night	x		x													x		
School Program with Child	x		x															
PTA Meetings																		
School-Site Council			x															
Parent-Teacher Conferences																x		
Only If Principal or Teacher Called Meeting			x								x					x		
Field Trips																		
Sports																		
504 Meeting								x										
Active in:																		
Back-to-School Night	x		x															
School Programs with Child	x		x															
PTA Meetings																		
School-Site Council										x								
Parent-Teacher Conference																x		
Classroom Projects																		

Field Trips																	
Sports	x																
Relationship with School																	
None				x			x	x								x	
Good										x							
Very Good	x					x						x					