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A COMPARATIVE STUDY OF THE EFFECTS OF CHILDHOOD CANCER ON SIBLINGS

A Thesis
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San Jose State University

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Introduction

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Introduction

Despite advances in pediatric oncology which have significantly improved the prognosis of children with cancer (Kramer, 1981), ". . . there is usually an implicit, if not explicit, awareness of the possibility of death" (Ross, 1978:258).

The average life expectancy of a child with cancer has been extended beyond two years, and there are growing numbers of children with "long-term survivals" (Futterman & Hoffman, 1973:129). Sigler (1970) found that some children are still alive and doing well five to ten years after leukemia was first diagnosed. However, for a child with leukemia, the norm is still extended periods of remission fraught with "episodic relapses and ultimate fatality" (Futterman & Hoffman, 1973:129). Approximately 2,000 children under the age of fifteen die from leukemia each year (Medical World News, 1971:37).

Although the extending of the ill child's life is what all families hope for, to the family members this also means prolonging the stress, tension, anxiety, and fear of death.

Considering the impact that one family member has on all others, it is no wonder that the entire family system is disrupted when a child has a life-threatening illness. But the impact of loss or threatened loss is different for the parents than for the child himself or the siblings. The parents suffer the loss of the hopes and dreams invested in the child. The ill child faces fears of abandonment and disfigurement, and the sibling faces fears, guilt and lack of parental attention. The effects are far-reaching.

It has been found that the adult ego develops out of childhood experiences (Hilgard, 1960). Therefore, the child's experience with the illness and possible death of his sibling shapes him forever. Bereavement in childhood not only contributes to the way a child copes with similar crises in the future, but it has also been shown to affect the course and speed of a child's emotional development (Burton, 1974).

"Siblings have many positive, growth-promoting, reality testing, learning-facilitating significances for each other" (Pollock, 1978:446). As he points out, esteem, recognition, and self-regard stem from sibling interaction, and social abilities, interpersonal and professional relationships may also be founded in sibling relations during childhood (Pollock, 1962). Thus a child's development is severely affected by the loss, or threatened loss, of a sibling.

From a systems perspective, what affects one family member affects the others. This holds especially true when a chronic illness is involved. However, most of the attention during a crisis of this nature is focused on the sick child and the parents; siblings are neglected. Therefore, the purpose of this study is to measure how children are affected by living with a sibling with cancer.

It is hoped that the results of this study will provide data that will document to what extent siblings are affected by childhood cancer, and will motivate professionals to provide care for the entire family, not just for the parents and the sick child.

Providing this level of care entails more than just identifying the symptoms in the siblings that indicate an emotional problem. It is important to prevent maladjustment as these problems may be potentially disabling in the child's future. Therefore, early intervention must be directed toward all family members of children with cancer so as to prevent emotional or psychological problems.

CHAPTER 2

Review of the Literature

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Review of the Literature

The rate of survival for children with cancer has increased recently due to treatment discoveries; therefore, it is important to assess the "overall impact on siblings of living with a chronic cancer patient" (Gogan, et al., 1977:42). However, most of the literature available today that addresses siblings focuses on "'the sibling of the dying child' rather than on 'the sibling of the child with a life-threatening illness'" (Sourkes, 1980:53). Consequently, insufficient literary attention has been focused on the aspect of living with a long-term, life-threatening disease. Relatively few of the resources surveyed in the literature focus on the feelings of the sibling during the illness phase, and, in fact, much of the literature that was found in this search studied the sibling's reactions following the death of a child.

It is important that the issue of long-term or chronic illness be studied as it has been found to be even more stressful than acute illness, and as it "taxes the emotional and physical reserves of all family members" (Taylor, 1980:109). As Iles points out (1979:132), this kind of data could prove useful in "refining the targets" of family, specifically sibling intervention.

Volumes have been written describing the parents' reactions to their child's cancer and/or dying, and there is substantial data on a child's reaction to his own illness and death. There is even literature on how teachers (Gyulay, 1978) and doctors (Schowalter, et al., 1983) are affected by the tragedy of a fatally ill child. Some research has gone beyond looking at the ill child or the parents as an isolated unit to focus on the family as an interactive whole. Unfortunately, articles were also found that indicated that a study of the entire family had been conducted, when in actuality, only the parents, or the parents and ill or deceased child were discussed (Futterman & Hoffman, 1973; Friedman, 1967). This certainly does not reflect the entire family, and it appears these authors were unaware of their neglect of siblings as part of the family constellation. It is important to attend to children's reactions to sibling loss because, if Sanders is correct in stating that the loss of a child is the most difficult loss for a parent to endure (Sanders, 1980), then that parent's preoccupation with his own grief presents the remaining children with a double loss--both the deceased brother or sister and the parent (Schumacher, 1984).

There is a substantive lack in the existing research in the number of studies that measure the effects on siblings. Some authors have done case studies, many more have chosen descriptive methods to illustrate the effects on siblings, and only six studies were found during this literature search that measure the severity of the effect that childhood life-threatening illness has on siblings (Cairns, et al., 1979; Burton, 1974 and 1975; Koch-Hattem, 1986; Taylor, 1980; Peck, 1979; Farkas, 1974).

Many researchers who studied siblings obtained their populations from patients in psychiatric facilities. Few studies were found that studied children who had a sibling with cancer when the sibling showed no outward signs of intellectual or emotional dysfunction.

To provide the reader with more generalized knowledge about how childhood cancer and similar life-threatening illnesses affect the family, this literature review will include information about the sick or dying child's reactions to his own illness, and how other family members are affected.

The Family

A long-term, life-threatening illness creates "prolonged periods of family disequilibrium" (Kramer, 1981:155). The severe illness or death of a child affects the entire family, each member in different ways, rearranging family patterns, traditions, and roles (Share, 1972). The family equilibrium must make a major shift with the loss of a child who had occupied the center of attention for an extended period of time. Krell and Rabkin (1979) found that the surviving children will try to fit the climate created by the parent. "If the circumstances of the tragedy are clear, adaptation is possible" (Krell & Rabkin, 1979:472). If, however, the parents are unable to deal with the loss, the siblings will "receive new roles to help obscure the loss" (Krell & Rabkin, 1979:472).

In a study of families done by Kaplan, et al. (1973:65), it was found that 87% of the families they studied had "failed to cope adequately with the consequences of childhood leukemia." If the parents failed to adequately cope with the tasks of the illness, this "largely precludes sound coping by the rest of the family" (Kaplan, et al., 1973:68). This failure to cope was found to create individual and interpersonal problems in addition to those stresses created by the illness itself.

Binger, et al., (1969) studied 23 families who lost a child to leukemia within a three-year period. Eleven of these 23 families had one or more members who had emotional disturbances following the death that were severe enough to interfere with functioning and to require psychiatric help; "none had required such help before" (Binger, et al., 1969:417). Several of these people required admission to a psychiatric hospital because of severe depression.

This study also found that each person reacts to the fatal illness of a family member "in a manner consistent with his own personality structure, past experience, current crises, and the particular meaning or special circumstance associated with the loss threatening him" (Binger, et al., 1969:418).

The Ill Child

To the child with cancer, death and dying are deforming experiences, bringing loss of identity and separation (Rhodes & Vedder, 1983). Although the patient may know that death means the end of life, he may be bothered most by a fear of being deserted (Rhodes & Vedder, 1983). Because of this fear of desertion and separation, the dying child places more demands on his parents and siblings.

Studies indicate that the child may become more angry at the healthy siblings after the diagnosis than prior to it (Koch-Hattem, 1986). The older the child is, the more aware he is of his own identity and his place in the family, and the greater he will feel the anticipated loss of his family and the relationship he shares with each of its members (Easson, 1970). When a child has cancer, he needs more reassurance that he is important and loved.

Time takes on a meaning for the cancerous child which is not usually found in young children. Most children perceive time as eternal, unmeasured, but the child with cancer is concerned about the time he has left (Rhodes & Vedder, 1983). This is apparent in that the sick child will often push himself to get things done or get angry with people who take too long to remember things, answer questions, or bring things to him (Rhodes & Vedder, 1983).

When hospitalized, ill children react strongly to being away from home. They frequently complain about being alone, cold, in the dark, or behind a closed door (Smith & Schneider, 1969). They often do not understand or trust the strangers that surround them (Easson, 1970). To make matters worse, these strangers cause the child pain; the child needs the security, comfort and love of his parents. Hospitals, having recognized this need, are beginning to allow parental participation in the child's care, and will sometimes provide arrangements for the parent(s) to stay in the hospital with the child (Kubler-Ross, 1981). This, however, can have far-reaching effects, as will be discussed in the section on siblings.

The ill child receives messages from hospital personnel, family and friends about a "right" way to die (Easson, 1970). He will learn that some of his responses to illness and his fears of death are acceptable, while others must be held inside so people do not become angry or upset (Easson, 1970). He also learns that he cannot show open wounds or talk too directly about the pain he feels, because that, too, will make others upset (Easson, 1970). The child will find that his family and hospital staff will respond much more favorably to a few smiles than to pain and anger (Easson, 1970). Remarkably, the child is forced to deal with his illness and possible death like an adult.

The lack of open verbal communication in the family goes far beyond the patient's inability to discuss his pain and fears. It permeates each relationship within the family every day throughout the illness and often continues even after the child recovers or dies. The lines of communication that do stay open are rare but poignant: body language and intuition. Burton found that sick children from families who previously had a seriously ill child, or who had a child die "were significantly less able to talk normally of their illness when compared with sick children from families with no loss" (1975:222).

The "merging" of identity a young child feels with his parents prevents him from understanding death as the end of his identity. However, a result of this merging of identity is that the feelings of the parents and the family are communicated to the child and become the child's feelings as well (Easson, 1970). For instance, if the child's father's eyes fill with tears when he looks at the child, the child will feel sad without really knowing why. Parental expressions of grief may be perceived by the sick child as anger or disappointment (Rhodes & Vedder, 1983). It becomes important that the parents tell the child why they are showing certain emotions so the child does not feel guilty, unwanted, or unloved (Rhodes & Vedder, 1983).

The Parents

Most parents respond to the diagnosis of their child's illness with the natural defense mechanism of denial. Binger, et al., found that the diagnosis was the "hardest blow" for parents throughout the illness (1969:414). Denial is used as a defense mechanism much more by fathers than by mothers during the period of anticipatory mourning. Fathers are also found to use denial for a longer period of time than mothers (Knapp & Hansen, 1973). With time, and further information from the physician, parents are more able to accept the diagnosis and the need to deal with the illness constructively (Schowalter, et al., 1983).

Some parents choose protective attitudes toward their child, and although after a time the child often knows his diagnosis, no one talks about it (Schowalter, et al., 1983). This silence places a barrier between the patient and the family that contributes to the child's feelings of isolation and prevents him from expressing his emotions (Schowalter, et al., 1983). Knapp and Hansen (1973) found that most parents are worried about what to tell the child if he asks, "Am I going to die?"

Chodoff, Friedman, and Hamburg (1964) studied parents and found that anticipatory mourning is prominent. The parents seem more detached from the child as the illness progresses. A normal part of the grieving process is anger at the loss of the loved one (Easson, 1970). As this anger cannot be directed at one tangible object, the anger is often expressed in destructive and self-destructive ways. Family members often feel guilty because of the anger they feel toward the ill child for threatening to leave them (Easson, 1970). Since this anger is not expressed to the patient, family members need some way to ventilate their feelings. As they are seldom offered constructive avenues for its release, family members often turn the anger on each other (Easson, 1970).

Regardless of how stable the marital relationship is before the illness, it is tested to its limits, and often beyond, during the course of the child's treatment and after the child's death (Gyulay, 1978). Although a tragedy often brings people together, with the loss of a child, each parent is affected by the loss of a primary person, and each parent's needs in this grief are great (Gyulay, 1978). As a result, one's major source of emotional support is taken away because the other is engulfed by his or her own grief (Rando, 1985). One of the most difficult aspects of parental bereavement is that the death of the child affects both parents simultaneously and confronts them both with the same overwhelming loss.

Parental grief involves not only dealing with the loss of the child, but also the loss of part of one's self, because "parental attachment consists of a mixture of object-love and self-love" (Rando, 1985:19). A study conducted in 1980 of 102 bereaved individuals found that the death of a child created the highest intensity of bereavement as well as the widest range of reactions (Sanders, 1980). Parental grief was found to result in greater depression, anger and guilt than did those mourning the loss of either a parent or spouse (Sanders, 1980). It must be noted, however, that bereavement over the loss of a sibling was not included in this study.

The intensity of bereavement is attributed to several factors. One major factor is the "unnaturalness" or "untimeliness" of a child dying before the parent (Rando, 1985:20). This represents a threat to the parents' sense of "eternity of self" (Rando, 1985:19).

According to Rando (1985), parents are also "multiply victimized." Not only do they suffer the loss of the child they love, but they also lose the hopes and dreams that were invested in that child. It is not uncommon for parents to mark the time when the child would have graduated, married, and so on. Parents with other healthy children are forced to function in the very role they are trying to grieve for and relinquish. When the parent believes he or she is not providing for the healthy child as well as he or she should, due to his or her preoccupation with the ill or deceased child, the parent feels a greater sense of failure, guilt, and depression. In their work with families, Soricelli and Utech (1985) found that, although parents expressed concerns for the siblings, in the first year of grief many parents experienced difficulty in consistently helping their children cope due to the parents' own needs.

The lack of communication that results when both parents grieve so deeply only adds to the strain on their relationship. One spouse may misinterpret the grief behavior of the other as hostility or lack of caring (Rando, 1985). Spouses may engage in grieving styles that are so different that it furthers the gap between them. Parents mistakenly assume that since they have suffered the same loss, they will share the same grief (Rando, 1985).

Chodoff, Friedman, and Hamburg (1964) studied 27 fatally ill children. While they found that several mothers became pregnant during or immediately following the child's illness, studies by Peck and Rando found the opposite. In

Peck's (1979) study, many parents decided against further pregnancies because of the sick child's diagnosis and Rando (1985) found that the preoccupation that accompanies the illness and grief, as well as the fear of having and losing another child often inhibits sexual responses and intimacy. This lack of sexual intimacy further isolates the parents. Rando found that although the intimacy of sexual contact may be comforting to (and needed by) one parent, it may be something the other cannot endure. It is not uncommon for a couple to have sexual problems in terms of lack of interest, depression, or sexual dysfunction, for up to two years following the child's death (Rando, 1985).

In a traditional family style where the husband works outside the home and the wife is the homemaker, the father may find that his usual role at work affords him some respite from the grief. The mother, on the other hand, may find that going about her daily routine only reminds her of the deceased child (Rando, 1985). Because the child's illness predominates, the day-to-day problems may not be confronted, but rather allowed to accumulate until there is an explosion (Rando, 1985) and children of all ages are affected by the marital tensions (Cairns, et al., 1979).

The Sibling

Despite the previously mentioned reasons for providing support to the siblings of seriously ill children, the well children in the family are often forgotten because of the needs of the sick child. Their achievements are sometimes ignored, and sport events or performances often go unattended. Some activities may even have to be stopped as neither mom nor dad are able to drive the child to peer group activities (Sigler, 1970). These activities are also missed because the well siblings take over some responsibilities of the home, namely cooking, cleaning, and caring for younger children.

Sometimes siblings of a child with cancer will adopt a "proxy parent" for the duration of the illness (Gyulay, 1978). While the sick child has the attention of the parents, other relatives, the doctors and nurses, and even the counselor (if one is sought) the patient's siblings must face these major changes without support (Gyulay, 1978). As Schumacher puts it, "Surviving siblings are often afterthoughts" (1984:84).

The impact of the illness varies according to the age of the sibling (Kramer, 1981). The infant needs consistency of warmth, love, and sensory stimulation in order to gain a sense of trust (Kramer, 1981). The absence of one consistent nurturing figure, specifically mother, can interfere with the child's ability to learn trust. From the age of two until four, the child is trying to develop a sense of autonomy. During this time the child needs to have his mother within eye sight as parental separation induces fear of abandonment (Kramer, 1981). Thus, the mother is split. If she spends her time with the sick child, the sibling must face these developmental steps without the necessary aid of mother. Yet if she stays at home with the siblings, the ill child will go through these steps without her. For the pre-school age child, the emphasis is on participation and performance (Kramer, 1981). Siblings often have to stop their peer group activities because neither parent is available for transportation to the activities. Although the school-age child has an increased ability to understand the necessary changes, he still resents the limitations on his activities (Kramer, 1981). Adolescents are better able to deal with the changes at home and with the lack of parental attention because they can understand abstract thought and higher order reasoning (Kramer, 1981).

Siblings, particularly if over the age of four or five years, are concerned with the dying patient, and they may be afraid for themselves (Koch-Hattem, 1986). Although it is expected that older children can temporarily assume the parental role for the younger siblings at home, even teenagers react to parental withdrawal and "act up" during these times (Schowalter, 1983).

The sibling's behavior may look as if he's asking for punishment, as frequently siblings have accidents, and delinquency is common (Burton, 1974). Kellerman (1980) found in a case study that the sibling's anti-social behavior was related to the mother's placement of all her hopes and expectations upon the well child. With the redistribution of expectations and pressures, the sibling stopped these inappropriate behaviors. Siblings unable to appropriately tolerate depression utilize defense mechanisms. Often this manifests itself in clowning or acting out behaviors, yet the child's facial expression in unguarded moments show his true emotions (Burton, 1974).

The siblings studied by Taylor indicated feelings of inadequacy and inferiority (1980). This same study reports that siblings felt "they could never do anything 'good enough' to get the parent's attention, or to earn status similar to the ill child" (Taylor, 1980:114). Taylor attributes this to the lack of feedback from the parents. Cairns, et al. (1979) found that older siblings have concerns about failing: they had four times the number of failure responses as the patients and younger siblings.

Most of the reviewed literature indicates that siblings show significant behavioral problems, indicating maladaptive coping patterns. The following are the most frequently cited: severe enuresis, headaches, abdominal pain, poor school attendance and performance, depression, severe separation anxieties, eczema, and asthma (Binger, et al., 1969; Burton, 1974). Regression frequently occurs in young children following the diagnosis of cancer in a sibling, and recently acquired activities are frequently lost (Burton, 1974).

Psychosomatic symptoms such as eczema and asthma often occur in siblings; unconsciously or consciously they feel that the only way to obtain parental concern is to become ill, yet they are also afraid to become like the patient (Sourkes, 1980).

The confusion that some siblings have about the seriousness of the illness may result in the well child wishing to get sick (Fienberg, 1970), or his imitating the mannerisms of the sick child (Gyulay, 1978). For instance, the well child may insist on taking vitamins to copy the patient's ingestion of medications. There are times when the sibling may think he is more ill than the patient, especially if the latter is in remission. To the sibling who is not feeling well, there is little difference between his illness and the patient's, except that the patient gets all the attention (Kramer, 1981). Confusion or misunderstanding about the illness may make a sibling afraid that the cancer is contagious (Taylor, 1980). As Sourkes points out, the child knows from past experience that illnesses affecting one family member are often transmitted to others. Thus, cancer is just an extension of this. Sourkes does point out, however, that this is especially true when the sibling is unable to emotionally or intellectually understand a cause for the illness. The well child may even be afraid that he will die next (Vore & Wright, 1974), or the child may be afraid to go to the doctor for fear that he will find out that he, too, has cancer (Cairns, 1979). Burton (1975) found this to be especially true in younger children; however, her definition of "younger" was not explained.

Many studies also indicated that siblings fear the child will die, and are unable to discuss this with their parents (Taylor, 1980). The siblings expect that when the child comes home from the hospital, all will return to normal (Kagen-Goodheart, 1977). In light of these expectations, one can predict that siblings will be resentful toward the patient and angry at the parents.

The sibling's task during the phase of living with a child who has a life-threatening illness is "to coordinate the concepts of constancy and change, sameness and difference" (Sourkes, 1980:58). The child has to learn that although chemotherapy or amputation may change the patient's outward appearance, the patient is still the same person he was before the illness. On the other hand, the sibling must also know that despite the child appearing to be the same physically, as occurs with leukemia, inner changes are making the child ill (Sourkes, 1980). A source of stress for the well children are the physical changes seen in the patient: hair loss, weight loss, or amputation (Cairns, et al., 1979). Concern over these physical changes are greatest among those siblings who are in their adolescent and pre-adolescent years (Kramer, 1981). This is true because of the hyper-sensitivity to their own body and to body images.

Siblings are often denied the truth of the sick child's prognosis because parents do not think the child can cope with the knowledge (Gyulay, 1978). In this instance, the siblings feel the parents' anxieties and emotional withdrawal without understanding why (Kramer, 1981). The well child's patience and generosity is often tested to its limits as he is forced to cater to the patient's wishes, and humor his anger, tantrums, and needs. It is difficult for siblings who are not fully informed of the illness to understand the deviations from the normal routine. In a study conducted by Iles, only one of the five siblings she interviewed was satisfied with the information that parents shared with regard to the "illness experience" (Iles, 1979). Burton found that only 53% of the 58 mothers she interviewed had discussed the illness with the well children (Burton, 1975). With this lack of communication, if the child dies, the sibling has had no opportunity to prepare for the death. Blinder (1972) found that siblings experience anger because the parents knew the possibly fatal outcome, but did not tell the sibling, thus denying him the chance to prepare for the death. As Ross (1978:268) points out,

> Adults experience shock if they are unprepared for the death of a loved one. Children also have extreme reactions when death occurs without prior warning . . . We want to protect children from death, but in so doing, we expect them to deal with it in one lump sum.

Vore and Wright also emphasize that if the child is not allowed to proceed through a preparatory grief phase, then problems arise "weeks, months, and perhaps even years following the child's death" (1974:144).

Also, if the child dies, those parents who have not previously communicated with the siblings in an open manner continue that pattern about the subject of death. Dishonest communication about the illness has been found to create distrust, and it undermines the relationship between the parents and children (Kaplan, et al., 1973).

Family members frequently attempt to protect the siblings from the realities of death with "philosophical and religious speeches" (Schumacher, 1984). This only serves to confuse the child and complicates the grieving process.

Albertson shows that explanations such as "'Mommy has gone on a long trip' may cause the child to wonder why Mommy left without saying goodbye" (Albertson, 1980:158). Also, explanations such as "God wanted her to be in heaven with Him," may, as Albertson explains, result in the child developing "deep distrust and anger toward such a God" (Albertson, 1980:158).

Cain, Fast and Erickson (1964:746) found that among their population of siblings, those children who had always been taught that people do not die until they are very old, "struggled with the clear contradiction to this of their sibling's death, and its corresponding undermining of their confidence in adults' pronouncements." This same study found that children's ideas of their parents' strength as protectors "came crashing." And Sourkes (1980) reports that the siblings she studied expressed anger toward the parents for not protecting the patient from the illness.

The relationship between the patient and siblings changes continuously throughout the illness (Gyulay, 1978). What was a stormy or distant relationship at the time of diagnosis may become a close relationship if the patient nears death. In Burton's study of 58 children with Cystic Fibrosis, having a total of 112 well siblings, only 23% of the families said there was no obvious change in the siblings' attitudes toward the sick child (1975). While almost half of the older siblings showed protective attitudes toward the sick child, younger children's reactions were less positive, including extreme jealousy (Burton, 1975).

Jealousy, rivalry, anger and subsequent guilt are common emotions in a sibling who must watch someone else occupy the center of attention (Fienberg, 1970). It is this lack of attention from parents that troubles most of the siblings studied in the existing literature. Taylor's research found that many siblings feel that the amount of time with the parents, and the level of parental attention was "inadequate to foster a good relationship" (1980:113).

Intensified sibling rivalry due to the attention received by the patient was noted in several studies. The study by Gogan, et al. (1977) found that long-term effects of sibling rivalry and guilt result, despite some parents' attempts to maintain the sense of normalcy. Pollock (1962) points out that siblings often feel guilty for being angry at the parents for allowing the child to become ill or die. Sometimes the well child who fears the unknown about death--where, when, how, and if it will happen--wishes it were over (Taylor, 1980). These feelings may cause guilt. Despite the need to express these feelings, sharing them with family may cause outbursts and still more guilt (Gyulay, 1978).

Some of the greatest guilt the sibling experiences is often because he may have once wished that he was an only child, and he fears that somehow he made that wish come true.

If the child dies, the sibling may feel still more guilt. The sibling may feel guilty for being healthy (Burton, 1975), for being the survivor when he may feel he is the more expendable of the two (Koch-Hattem, 1986). The feelings of survivor guilt extend to having fun and making plans for the future (Gyulay, 1978). Often siblings are afraid to establish a new life without the child for fear that others will think the child did not care about the deceased. Schumacher finds that to siblings, perhaps going on with their life means that they did not care (Schumacher, 1984).

Cain, Fast and Erickson studied 58 children in a psychiatric setting, and discovered that "the primary if not the exclusive pathological impact of a sibling's death upon the surviving child is one of guilt" (1964:743). This study found that the guilt was "still consciously active five years or more after the sibling's death." Farkas' study indicates that children in those families that openly discuss the illness feel less guilt than do those children from more closed families (Farkas, 1974).

The living child is a reminder to the parents of the child who died, and the parents' anger and pain may be poured onto the well sibling, causing the child still further guilt (Rando, 1985). Because the child is expected to fill the void left by the patient if he/she dies, the sibling finds himself in a double bind situation (Rando, 1985). If the sibling succeeds in filling the void, he is living the chance denied the deceased child. If he fails, he is not using his potential--one that was denied the deceased child (Gyulay, 1978). Coupled with this double-bind situation, the sibling finds himself representative of both himself and the deceased child, and parental over-protectiveness often results in "enhanced expectations" (Krell & Rabkin, 1979:473).

Occasionally families feel that there is a better medical facility outside the city where the family lives. Thus some families will choose to send the child out of the area, and even out of the state, to receive the "best" medical treatment. Frequently the mother will move to remain with the child during the treatment. With Mom gone and with Dad working, the children are frequently sent to live with other relatives or family friends. Even if the patient stays in the area and the mother lives at home, the siblings can be deprived of their mother because she may take advantage of many hospital's programs that allow a parent to remain in the hospital for days at a time in order to participate actively in the child's care. Although these programs are beneficial to the child who is sick and comforting to the mother, it has been found that it can also negatively affect the child's siblings (Cobb, 1956). In a study conducted by Peck (1979), of those families who reported having problems with siblings, many of these problems began while the mother was living in the hospital with the child and the siblings were living outside the home, usually with other relatives. The well child loses not only parental attention, but also the physical presence of his parents (Share, 1972).

Iles's study reported that "two areas of difficulty most often reported by the siblings included the 'empty house' and the presence of parental substitutes" (1979:374). Despite the literature that seems to indicate negative effects on siblings when the mother was absent and parental substitutes took over, Gogan, et al. (1977) found, in their retrospective study, that none of the children they studied remembered feeling abandoned. The researchers attribute this to the fact that in some cases, the mother had worked prior to the diagnosis, and thus the siblings had been reared by parental substitutes (Gogan, et al., 1977).

Two-thirds of the statements made by siblings in a study by Taylor (1980) revealed that they experience feelings of isolation, deprivation, inferiority, or inadequate knowledge about some aspect of the child's cancer. The largest single effect of the illness process was the siblings' feelings of isolation (Taylor, 1980). Many of the children Taylor studied described feeling "alone or outside the family relationships" (1980:113).

The sibling's peers can be supportive during this time, but often these peers only add to the pressures the well child feels. The sibling may be forced to defend the patient when disease or disfigurement make him the object of ridicule (Burton, 1975). Siblings often feel that their friends do not know what they are experiencing, and they have trouble knowing what to tell their friends (Schumacher, 1984). Schumacher's study (1984) found that siblings were frequently avoided by old friends and in the study conducted by Iles, all of the siblings reported altered peer relationships (Iles, 1979). This rejection further isolates the child. The sibling rarely turns to his parents with these problems; he fears he will simply add to their grief (Cairns, et al., 1979).

The long-term effects on the siblings include the acquiring of hobbies previously enjoyed by the now deceased child (Cobb, 1956), and reactions to the anniversary of the death of the child (Hilgard, 1969:200). An example Hilgard cites is a child who, when seen at Agnews psychiatric facility in California, was in a wheelchair, and was not speaking, eating, or moving. The girl was eleven and a half, the same age as her sister when she died. Within a few weeks of treatment, the girl was back walking, eating, and talking. Hilgard explains that the patient "had reacted by reproducing death on a symbolic level" on the anniversary of the death of her sibling.

Despite the literature cited above that indicates siblings go through major changes as a result of living with a child with cancer, Koch-Hattem (1986:110) found a significantly greater number of siblings reported "no change in their experiences following the diagnosis than reported either negative or positive changes . . . this was particularly apparent in regard to depression or anxiety." However, in the same study, siblings also reported "feeling bothered, sad and scared more often following the patient's illness than prior to it" (1986:112).

It cannot be assumed that all the effects of living with a child with cancer are negative. Siblings report some positive results of the illness experience as well. Several of the siblings interviewed by Iles (1979) reported a feeling of pride in their accomplishments regarding the care of younger children in the home. Kramer (1981) also found that taking on chores at home helps instill feelings of self-esteem in the well siblings. Each of the subjects in

Iles' study perceived gains in their knowledge and understanding of the physical responses to illness and treatment (Iles, 1979). Kramer (1981:160) found that well siblings "tend to mature earlier and not be so dependent on others." They also learn to be more flexible and adaptable (Kramer, 1981). Kramer also found that siblings develop a greater capacity for empathy, cooperation, and compassion (1981). Older siblings have been found to be able to comfort their parents during grief, providing not only a "sense of perspective" but also emotional support (Burton, 1975:221). Taylor's research, analyzing the statements of siblings indicate that one-third of the siblings' responses revealed positive effects (1980). These effects include cooperation, empathy, increased self-esteem, and cognitive mastery (Taylor, 1980). Gayton, et al. (1977:893), in a study of families with a child having Cystic Fibrosis, found that "the average total self-concept score for siblings is higher . . . than for normal children." However, Taylor (1980) concluded that the siblings are affected more negatively than positively by the illness, and Cairns, et al. (1979) went so far as to say that the negative effects of the illness process have at least the same, if not a greater impact on siblings than on the ill child.

Summary

In summation, the diagnosis of cancer in a child affects each family member in a unique, yet poignant way. Therefore, it is important to address the needs of the siblings while working with the parents and the ill child. To date, the emphasis both in clinical intervention and in research has been on the ill child and the parents, while the sibling has been virtually neglected.

Due to the lack of available literature that measures the effects on siblings, this research will add to the existing knowledge base by focusing primarily on the impact of the illness experience on the siblings alone.

CHAPTER 3

Methodology

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Methodology

Utilizing a quasi-experimental research design, the Family Relationship Inventory (1982) was administered to ten families in order to evaluate the severity of the emotional impact of childhood cancer on the patient's siblings.

The Family Relationship Inventory (FRI) was purchased through Psychological Publications, Inc., and was then administered to the ten families. Five families have a child who has been diagnosed with cancer, and in five families all children are in relatively good health.

Hypotheses

It is hypothesized that the siblings of children with cancer will have lower self-esteem scores than those children from a control group.

It is further hypothesized that siblings of a child with cancer will have a more distant relationship with family members than children from a control group.

Sampling

It was this researcher's original intention that a representative random sample be obtained by selecting families with a child receiving treatment for cancer at

San Francisco Bay Area children's hospitals. Despite this researcher's prolonged attempts at engaging the hospitals in this project, access to patients was denied. Consequently, the families for the experimental group were selected from those families participating in the Touchstone support group in Palo Alto, California. Families were invited to participate if they had a child with cancer and at least one sibling, age five or older, living in the home. Thirteen families met these criteria, and were invited by mail to participate in the study.

An information packet (see Appendix A) was sent to the thirteen families, and four responded. The information packet that was initially received included a letter of introduction from the staff at Touchstone. Also included was a brief description of the study and a form to be returned in an enclosed, stamped and self-addressed envelope for those families interested in participating.

In addition, one family was obtained when the Boy Scouts Association was contacted with regard to the control group. This family was contacted because the mother was a troop leader. Initially she was contacted by telephone by this researcher to engage her assistance in finding families who might be willing to participate in the control group. Upon discussing the nature of this research project, the mother indicated that her two-year-old daughter had leukemia, and that the family would be interested in participating in the experimental group.

The control group was obtained through several avenues. Administrators of the local chapters of the Girl Scout and Boy Scout Associations were contacted both by telephone and subsequent personal appointments, resulting in one control group family. It was not possible to obtain all control group families through these associations due to lack of interest on the part of those leaders and families involved with these associations. Therefore, announcements were made in graduate classes of the School of Social Work at San Jose State University in San Jose, California. This resulted in two families for the control group. The remaining families were obtained through a variety of means including announcements in graduate psychology courses at the University of Santa Clara in Santa Clara, California.

Families were eligible if they had at least two children living in the home over the age of five. These families were also eligible if the ages of the children closely corresponded with the ages of the children in the experimental group. Those who responded with interest to the announcements of the study were contacted by the researcher by telephone to provide further information about the study, to verify the ages of the children in the home, and to arrange for appointments to meet with the family.

In total, five families agreed to participate in the experimental group and five in the control group.

Data Collection Instrument

The Family Relationship Inventory (FRI) is a tool that examines family relationships. It is designed to clarify individual feelings and interpersonal behavior. According to the FRI manual (1982:1), "use of the FRI facilitates understanding of the family system: how each individual perceives . . ." himself, his parents, children, siblings, and other family members. It also examines how each person functions in relation to all others.

The FRI was developed from Dr. Ruth Michaelson's Family Relationship Scale. This scale was constructed to determine the degree of "social distance" between members of a family. In developing the FRI, the term social distance was broadened to include self-distancing and the degree to which one esteems and accepts self. Since its development in 1974, the FRI has gained acceptance among those professionals in the United States who work with children, adolescents and families. Favorable results have been reported using the instrument both as a diagnostic and a counseling tool.

The FRI is administered in the following manner:

1. Each family member has his/her own Tabulating Form (see Appendix B). On this sheet, the names of each person

in the family are recorded. Also included is anyone else who the participant would like to include (hereafter referred to as "significant other"). Suggested are grandparents, pets or babysitters. Also included on this sheet is a column titled "waste basket."

2. The researcher then reads the statement on each of fifty cards, and the number that corresponds with each statement in the order suggested by the authors (see Appendix C).

3. Each subject then records the number that corresponds to each statement under the name of the person it best describes: either self, any one of the other family members, or under the column labeled waste basket, if the statement applies to no one on the tally sheet.

Data Collection

All families were interviewed in their homes. The parents were asked to sign the consent form (see Appendices D and E), then they were asked questions regarding demographic information (see Appendix F). Subsequently, the FRI was administered to all those presently living in the household over five years of age. Due to the vocabulary used in the FRI, the authors of the test state it is inappropriate for children under five years of age.

Following the completion of each of the fifty cards, the researcher concluded the interview. Administration of the data collection instruments generally lasted approximately 45 minutes. However, the research occasionally remained in the home beyond the completion of the exercise, as some families volunteered information regarding their experiences with the illness process.

Data Analysis

The researcher scored the responses of all the Tabulating Forms. Those statements numbered from one to twenty-five have a positive valence, and those from twenty-six to fifty have a negative valence. The combined total of these numbers indicates the subject's self-esteem and his positive and negative feelings about each of the individuals listed on his Tabulating Form.

The data were analyzed by comparing the family from the experimental group to their matched family from the control group. Scores on self-esteem were compared along with the most and the least esteemed family members. The Tabulating Forms were analyzed to obtain information regarding the consistency with which children assigned certain characteristics to family members. The patterns found here are also included in the following chapter. Data were analyzed and comparisons between control and experimental group families were made to obtain data indicating any differences that may exist as a possible result of living with a child with cancer.

The t-test was employed to determine if the differences between the control and experimental groups were significant at the .05 level. Due to the small sample size neither the chi-square nor the z-test were utilized.

Major Variables and Their Operational Definitions

Ethnicity: The ethnic group children in the study identify with.

Religion: The religion family members identify with, regardless of frequency of worship.

Frequency of worship: The frequency of family members' worship, regardless of the location or formality of the worship ceremony.

Peer Group Activity: Any formally organized program or activity which involves two or more people of approximately the same age.

Approximate Annual Income: The combined total family gross income.

Formal Support Group: Any formally organized supportive environment, i.e., individual, family, or group therapy, peer support groups, etc.

Cancer: Any type of malignant neoplasm (Thomas, 1981).

Sibling: Any child living in the home with a brother or sister who has cancer.

Child: Any individual age 18 or younger.

Self-esteem: One's attitude toward self; one's self-appraisal (Family Relationship Inventory, 1982).

Most Esteemed Family Member: The person assigned the greatest number of positive responses by himself and other family members.

Least Esteemed Family Member: The person assigned the greatest number of negative responses by himself and other family members.

Closest Relationship Within the Family: The two people in the family whose scores for each other, when combined, are higher than any others.

Most Distant Relationship within the Family: The two people within the family whose scores for each other, when combined, are lower than any others.

Confidentiality

Confidentiality was maintained through the assignment of alphabetic and numeric codes to the members of families in both the experimental and control groups. These codes were assigned after the subject completed his or her Tabulating Form. This code was used during data analysis, and all Tabulating Forms and consent forms (with the subjects' real names) are kept in a closed file.

Limitations

The ability to generalize the results of this study is limited for three reasons. One, the sample size is too small to enable these results to be generalized. Two, the nature of the selection of the experimental group implies that these families have identified the need for emotional support and therefore these families may not be representative of the general population of families with a child with cancer. Three, the selective nature by which families for the control group were identified in order to provide a matched sample for the experimental group implies that the families in the control group may not be representative of the general population.

Despite these limitations, it is believed that this study may provide direction for further research that evaluates the extent to which children are affected by living with a sibling with cancer.

CHAPTER 4

Analysis and Results

CHAPTER 4

Analysis and Results

Ten families, with a total of 28 children, were studied for this research. Five families have a child with cancer, and five families have children in relative good health, serving as a control group. All families except one of the control group had both parents living at home. All families had at least two children living in the home between the ages of five and eighteen with the median age being 13 and a mean age of 12.43. Families from the control group were selected if the ages of the children matched the ages of those siblings in the experimental group who responded to the interview questions (see Table 1 for the matched families).

As the FRI is invalid for children under the age of five, only those children at least five years old were tested. The children in the control group whose ages correspond with siblings not tested were not tested either.

Table 1

Participating Families

	Experimental		Control	
	Age	Gender	Age	Gender
Family A	10*	girl	11	boy
	8	girl	8	girl
	3	girl	6	girl
Family B	17*	boy	17	boy
	11	girl	15	girl
Family C	17	girl	17	girl
	16	girl	16	girl
	13	girl	12	girl
	9*	boy		
Family D	18	boy	17	boy
	16	boy	15	girl
	2*	girl		
Family E	15*	girl		
	13	twin boys	13	twin boys

*Patient

Demographics

Four of the experimental group families and four of the control group families are Caucasian. One of the experimental group families is Hispanic, and the children in one of the control group families are Hispanic and Asian.

Family annual incomes ranged from $76,000 to $25,000 with a median and mean of $47,500 and $49,000 respectively. Four families of the control group and four families of the experimental group indicated a religious affiliation.

Among those parents who indicated that the family had a religious affiliation, only one child did not consider himself a part of that affiliation. Thus, 20 of the 27 children indicated a religious affiliation. Frequency of worship ranged from three times per week to those who have a religious affiliation but do not worship at all. The denominations represented include Catholicism and Judaism.

The age of the child with cancer ranged from seventeen to two years old with a median age of ten and a mean age of 10.6.

None of the families in the control group had a child who was seriously ill or disabled, and all of the siblings in the experimental group were also in relative good health. The diagnoses represented in the experimental group included Wilm's Tumor, Ewing's Sarcoma, and three children with Leukemia. The children were diagnosed between one and six years ago, with a mean time of 3.4 years since diagnosis. Two of the children are receiving chemotherapy, one is halfway through his initial treatment plan, the other relapsed two months before the interview and has two more years of treatment at this time. Two children have not relapsed and are in remission, one for three years, the other for two. One child relapsed in 1984 and has recently discontinued chemotherapy.

Ten children in the control group and eight children in the experimental group are involved in peer group activities. The activities represented include music, athletics, choir, drama, and boy/girl scouts. Nine children are not involved in any peer group activities. Only one family indicated that the patient and sibling stopped peer group activities following the diagnosis. The patient stopped athletics (his only activity) due to the loss of use of his legs, and the sibling stated she did not know why she stopped participating.

Results

Each family member identified his or her feelings about him/herself and the other family members. These feelings were then identified as positive or negative and self-esteem scores for each individual were obtained. These scores indicate how each person feels about himself in relationship to the family. Sibling self-esteem scores are illustrated in Table 2 below.

Table 2

Siblings' Self-Esteem Scores

	Experimental	Control
Family A	+5	+2
B	-4	+5
C	+2 -2 +2	0 -1 +3
D	0 -3	+1 -2
E	+3 -1	+4 +5
Mean	+0.22	+1.89
Median	0	+2
Range	9	7
Standard Deviation	2.82	2.43

Of the nine siblings studied, four assigned the characteristic "too busy to be with me" to the father, while none of the siblings indicated they felt this way about their mother. Four of the nine siblings responded to "loves me" by assigning this characteristic to their mother, while only one of the four patients did this. Four of the nine siblings assigned "truthful" to their mother whereas only one patient did the same. Five of the siblings believe their mother trusts them, whereas only one of the patients felt this way.

Five of the nine siblings assigned "complains or whines" to the patient, and three of the four patients attributed this same characteristics to the sibling. Only two of the siblings assigned "selfish" to the patient; however, all four of the patients old enough to take the test described their siblings as selfish.

There was no apparent difference in the scoring of the siblings who had a significant other they included on the FRI tabulating form with those who did not. Those children who did choose to include a significant other on their tabulating form chose to include a playmate or a pet.

By assessing which family members felt the best about each other, the strongest bond, or closest relationship was evaluated. The closest relationship within the family consistently involved the second child. The second most common bond was that between the two parents. Frequently the mother was most closely bonded with the second child. The exceptions to this were in the experimental group. In Family C the fourth child (the patient) and the second child had the closest bond, and in the E family, the twin thirteen-year-old boys (the second and third child) had the closest bond (see Table 4).

Table 3

Closest Relationship Within Each Family

	Experimental	Control
Family A	Mother and second child (girl)	Mother and second child (girl)
B	Mother and second child (girl) and both parents	Mother and second child (girl)
C	Patient (eldest) and second child (girl)	Mother and second child (boy)
D	Father and Mother	Father and Mother
E	Two twin boys	Father and Mother

Table 4 indicates that the most distant relationship within the control group families was between the children in all cases. However, in three of the five families who have a child with cancer, the most distant relationship was between the father and a well child.

Table 4

Most Distant Relationship Within Each Family

	Experimental	Control
Family A	Father and eldest child (girl)*	Third child (girl) and fourth child (girl)
B	Father and second child (girl)	Second child (girl) and first child (boy)
C	Fourth child (boy)* and third child (girl)	Third child (boy) and second child (boy)
D	Father and second child (boy)	First child (boy) and third child (boy)
E	Third child (boy) and first child (girl)	First child (boy and second child (boy)

*Patient

There appears to be no pattern in the person identified as the least esteemed within the families; however, in nine of the ten families, the mother was the most esteemed. The one exception, in an experimental group family, was the eldest child, a son who was the most esteemed.

Analysis

The t-test was utilized to determine the estimated standard error for the difference between two means, namely, the sibling self-esteem scores of the control and experimental groups.

The sibling's self-esteem scores, though apparently different, were not significantly different even at the .10 level. Therefore, there is no significant difference in the self-esteem of those children who have a sibling with cancer and those who have healthy siblings.

The patients, while not included in the closest relationships in any of the families, were found to be included in the most distant relationships in the families (see Table 4). This may be attributed to anticipatory mourning and thus supports Chodoff, Friedman, and Hamburg (1964) who found that parents became more detached from the patient as the illness progresses.

The father's relationship with his children may be changed when one of the children is ill. This is apparent in that in the control group, the most distant relationship is consistently between the children. In the experimental group, two of the five fathers had the most distant relationship with the well siblings and in one family the most distant relationship was that between the father and the patient.

Summary

In reference to the review of literature, the results of this study are consistent with the literature previously cited in that relationships within the family do change when a child has cancer. However, there are discrepancies between the findings of this study and the existing literature.

Despite sources which indicate that siblings must frequently discontinue peer group activities due to financial or transportation difficulties (Sigler, 1970), in this study only one of the nine siblings studied discontinued peer group activities since the child's diagnosis. Also, despite the researcher's directions at the time of the interview that any person other than immediate family members could be included "like maybe a grandparent, pet or babysitter," none of the siblings in this sample indicated they had another adult who had taken on the role of "proxy parent" as is indicted in the literature (Gyulay, 1978).

The literature indicates that children are often denied the truth about the illness (Gyulay, 1978). In this study, four of the nine siblings indicated that their parents were truthful. Literature has indicated that siblings feel abandoned due to the parents' preoccupation and physical absence during the illness (Taylor, 1980; Iles, 1979).

However, Gogan, et al. (1977) found that the children did not feel abandoned. Data from the present study also indicate that while four of the nine siblings felt that their father was too busy to be with them, none of the siblings reported the same feelings about their mother.

The findings indicate that the sibling relationship may not be different as a result of cancer. Many of the children reported that a sibling complains or whines, or is selfish, and these characteristics were assigned almost equally regardless of whether the child had cancer or not.

Neither hypothesis was verified by this research. The self-esteem scores of children in the experimental group were not significantly different from the scores of those children in the control group. The distance or closeness the sibling feels to other family members does not appear to be related to cancer in the family. However, the distance between the father and his children may be affected by a child having cancer.

CHAPTER 5

Conclusions and Recommendations

CHAPTER 5

Conclusions and Recommendations

Conclusions

This study can neither support nor refute the existing literature due to the inherent limitations in this study, namely the small sample size and the selective nature of the sampling process. What this research does, however, is contribute to the existing literature in that the findings indicate the sibling relationship between a child with cancer and his well siblings may not be different from families without cancer.

The FRI as a research instrument, in accordance with its validity and reliability, is a useful tool in measuring the dynamics and relationships in a family when a child has a life-threatening illness.

Neither hypothesis was verified by this research. The self-esteem scores of children in the experimental group were not significantly different from the scores of those children in the control group. Also, the distance or closeness within those family relationships involving the sibling appear to be unrelated to cancer in the family.

Recommendations for Treatment

It is recommended that all members of families of children with cancer receive formal intervention in the form of education and supportive therapy in order to prevent the negative effects illustrated in this research and previous literature. Parents should be encouraged to discuss the illness process with the children, and the well children should be encouraged to meet the doctors and nurses who treat the patient. The siblings should also be encouraged to meet individually with the physician to obtain information about the cause of the illness. This may prevent the child from believing he is responsible for the patient's illness.

Parents should be encouraged to maintain open communication about all areas of their lives, not only the child's illness and treatment. This is essential in maintaining a healthy marital relationship and therefore a healthy family.

The siblings should be encouraged to express their feelings, and to explore their beliefs about what caused the illness.

Recommendations for Future Research

It is recommended that quantitative data be sought which measures the degree to which families, and siblings in particular, are affected when a child has cancer. It is imperative, however, that a large random sample be utilized to prevent the limitations inherent in this study.

It is recommended that research be pursued which identifies not only how the sibling is affected by living with a child with cancer, but also investigates how the entire family is influenced. Specifically, how the impact on one family member affects all others.

It is further recommended that the impact of support groups be evaluated as an effective intervention strategy to prevent the serious emotional and psychological problems that the previous literature indicates may occur as a result of living with a child with cancer.

A final recommendation is that a longitudinal study be performed to observe the changes that the family encounters as a result of the different phases the patient progresses through, specifically diagnosis, treatment, remission, relapse, and death.

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*Citation format requested by Psychological Publications, Inc.

APPENDIX A

November 10, 1986

Dear Touchstone Families:

Teri Johnson, a social worker from San Jose, is working with us on a research project that will illustrate how families, especially siblings, are affected by a child's cancer. We think this is a valuable opportunity for your experiences to have an impact on the professionals' understanding of how childhood cancer affects families.

As it is only through understanding the needs of families that services can be effectively provided, please carefully consider whether you would like to participate in a study of this nature. If you are interested, or if you would like more information, please return the enclosed form.

Please be assured that we are working closely with Teri and we have suggested that your family may be appropriate for this study. All information is being kept confidential.

Sincerely,

Daychin Campbell Karen Csejtey

Dear Families:

Your family has been invited to participate in an exercise that will illustrate family structure and functioning. The purpose of this study is to compare the structure of families who have a child with cancer with those families with healthy children. If you decide to participate, I will meet with the family for approximately 45 minutes. During this time you will be asked to record your responses to certain statements in a game-like format. The exercise is such that no emotional or physical repercussions will result, and most people enjoy the game-like format.

Any information that is obtained in connection with this study and that can be identified with your family will remain confidential. If you decide to participate you are free to discontinue participation at any time without prejudice.

If you may be interested in participating in this study, or if you would like more information, please complete the form attached and return it in the envelope provided. If you have any questions or concerns, please feel free to phone me at the numbers listed below.

Thank you for your interest in this study.

Sincerely,

Teri Johnson

Telephone Numbers: Days: 415/493-5000, ext. 2388
Eves: 408/224-0940

Research on Childhood Cancer

☐ Yes, I am interested in participating in your study. Please contact me to arrange an appointment.

☐ I may be interested in participating in your study. Please contact me with more information.

Name ____

Telephone (day) ________________ (eve) ________________

Age of sick child ________________

Ages of well children in the home ________________________

Please return this form in the envelope
provided by December 12, 1986.
Thank you,

Teri Johnson

APPENDIX B

Your Name ____________________

Age ________ Sex ________

FRI TABULATING FORM

Names								Wastebasket
Total +	+	+	+	+	+	+	+	+
Total –	–	–	–	–	–	–	–	–
Total Score								

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APPENDIX C

FRI ITEMS: SUGGESTED ORDER OF ADMINISTRATION

Trusts Me (3)
Shy-afraid of people (30)
Strong - dependable (4)
Bright - smart (9)
Pretty - nice looking (6)
Listens to me (8)
Usually calm, peaceful (15)
Tattletales - tells on me (49)
Won't tell me (5)
Never on time - usually late (40)
Remembers special things I like (25)
Usually smiling and cheerful (18)
Too noisy (29)
Lively - enthusiastic (7)
Always at home when I need them (20)
Truthful (13)
Complains - whines (33)
Selfish (41)
Doesn't rush me-waits for me (10)
Makes me do too much work (48)
A poor loser (37)
Makes me happy (24)
Too strict with me (34)
Fun to be with (17)
Yells and screams a lot (45)
Usually on time-punctual (19)
Loves me (1)
Tells lies (39)
A good sport-likes jokes (11)
Keeps promises (16)
Stupid-dumb (31)
Messy-dirty-grubby (35)
Likes to kiss me (14)
Tells me secrets (23)
Show-off-acts silly (44)
Excitable (47)
Hates me (27)
Hits and slaps people (42)
Tries to act fair (2)
Has a lot of friends (22)
Not a "show-off" (21)
Too bossy-always giving orders (32)
Frowning-gloomy (38)
Teases everyone (36)
Never believes me (26)
Shares with others (12)
Too big and fat (28)
Cheats-is sneaky (43)
Too busy to be with me (46)
Talks too much (50)

Psychological Publications, Inc.

February 10, 1987

Mrs. Teri Lynn Johnson
4200 The Woods Dr., Apt. B-83
San Jose, CA 95136

Dear Mrs. Johnson:

We are writing relative to your letter of February 3, 1987 in which you ask permission to photocopy page 17 of the Family Relationship Inventory (FRI) Manual for inclusion in the appendix in your Masters thesis. We hereby grant you permission to reproduce page 17 of the FRI Manual soley for the purpose of its inclusion in your Master's thesis. We do request that the following statement appear at the bottom of this page, "Reproduced by permission of Psychological Publications, Inc."

We also prefer our bibliographical reference to read as follows:

> Family Relationship Inventory, Michaelson, Ruth B. and Bascom, Harry L., 1982 revision by Taylor, Robert M., Morrision, W. Lee, and Nash, Louise, by Psychological Publications, Inc., 5300 Hollywood Blvd., Los Angeles, CA 90027. 1982.

We shall look forward to learning more about the results of your study and when possible to receiving a copy of your completed thesis.

Sincerely yours,

Jamie T. Walkow

Jamie T. Walkow
Associate Director

JTW:jd

5300 HOLLYWOOD BOULEVARD • LOS ANGELES, CALIFORNIA 90027 • TELEPHONE (213) 465-4163

APPENDIX D

Consent Form

You and your child(ren) are invited to participate in an exercise that will enable a sibling's reactions to childhood cancer to be studied. We hope to learn how the siblings of seriously ill children are effected by the treatment regimen, the serious consequences of the illness, and the change in their daily schedules. You and your child(ren) are invited to participate because your child was diagnosed as having cancer.

If you decide to allow your family to participate I will meet with you and your child(ren) for approximately 45 minutes. During this time you and your children will record your responses to certain statements in a game-like format. You and your child(ren) will not be asked any questions pertaining to medical treatment or illness and the exercise is such that no emotional or physical repercussions will result.

Any information that is obtained in connection with this study and that can be identified with you or your child(ren) will remain confidential and will be disclosed only with your permission or as required by law.

If you allow your family to participate, you are free to withdraw your consent and discontinue participation at any time without prejudice.

If you have any questions, please feel free to ask. If you have any further questions, you may phone Dr. Hector Garcia at (408) 277-2235 and he will be happy to answer them.

You are making a decision whether or not to participate. Your signature below indicates that you have decided to participate and to permit your child(ren) listed below to participate having read the information provided above.

Date

Parent's Signature

Parent's Signature

Signature of Investigator

Name Age

Name Age

Name Age

Name Age

Name Age

Name Age

APPENDIX E

Consent Form

You and your child(ren) are invited to participate in an exercise that will enable the effects of a child's cancer on his/her siblings to be studied. You and your child(ren) have been selected as possible participants because none of your children are seriously ill and their ages correspond with siblings of ill children previously studied. We hope to learn how siblings of cancerous children are affected by comparing their test results to those of children from healthy families.

If you decide to allow your family to participate I will meet with you and your child(ren) for approximately 45 minutes. During this time you and your child(ren) will record your responses to certain statements in a game-like format. You and your children will not be asked any questions about illness or death. The exercise is such that no emotional or physical repercussions will result.

Any information that this obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

If you allow your family to participate you are free to withdraw your consent and discontinue participation at any time without prejudice.

If you have any questions, please feel free to ask. If you have any further questions you may phone Dr. Hector Garcia at (408) 277-2235 and he will be happy to answer them.

You are making a decision whether or not to allow your family to participate. Your signature below indicates that you have decided to participate and to permit your child(ren) listed below to participate having read the information provided above.

Date

Parent's Signature

Parent's Signature

Signature of Investigator

Name Age

Name Age

Name Age

Name Age

Name Age

Name Age

APPENDIX F

Demographic Questions

1. How many children are in your household at this time? _____

   If not all children are participating in this study, why not and what are their ages?

2. How many adults are in your household at this time? _____

   If other than mother and father, what is the relationship and his/her age(s)?

3. Do you have any religious affiliation? _____

   If yes, what denomination and how often do you worship?

   ____

4. What ethnic background best describes the child(ren) participating?

   (a) Black
   (b) Caucasian
   (c) Hispanic
   (d) Asian
   (e) Other

5. What grade in school is each child who will participate in the study?

   ______________ ______________ ______________

   ______________ ______________ ______________

6. Please approximate your average annual income $______________

7. What activities or peer group organizations do your child(ren) participate in?

   ____

   ____

   ____

   ____

8. Is anyone in the family participating in a formal support group? If yes, who? For how long? What type?

For experimental group only:

9. How old is the child with cancer? ______

10. What is the child's diagnosis? ______

11. How old was the child when he/she received the diagnosis? ______

12. Did both parents work prior to the diagnosis? Both now?

13. Are any other children disabled or seriously ill? If yes, who? and what is the illness?

For control group only:

14. Do both parents work? Have both always worked?

____

____

15. Are any of your children disabled or seriously ill? If yes, who? and what is the illness?

____

____

____

____