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Child hospitalization: the effects on well siblings and parents

Charlotte Rae Wallinga
Iowa State University

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CHILD HOSPITALIZATION: THE EFFECTS ON WELL SIBLINGS AND PARENTS

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Child hospitalization: The effects on well siblings and parents

by

Charlotte Rae Wallinga

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INTRODUCTION

Need for Well Sibling Research

Over 80% of American children today have at least one sibling with whom they interact a great share of the time (Brody & Stoneman, 1982). Lamb's studies (1978) show that younger children will watch and imitate older brothers and sisters. Furthermore, sibling relationships have been viewed as major avenues for the socialization and development of young children (Brody & Stoneman, 1982; Hobson-Flake, Robinson, & Skeen, 1983). Due to the lengthy and close early relationships, siblings often become closely attached to one another (Hobson-Flake, Robinson, & Skeen, 1983). Thus, when a child is hospitalized, the resulting induced separation may disrupt the sibling bond and cause increased difficulties within the family system (Spinetta, 1978).

> Few investigations have gone beyond the focus on parent child interaction to a more complex "system approach" studying the entire family interacting with one another. The siblings who comprise an important component of the family system are seldom studied (Gogan, O'Malley, & Foster, 1977, p. 44).

Everson (1977), addressing the need for sibling counseling or intervention, wrote, "If we truly espouse the need of family-centered care, then we must look beyond the care of those in the immediate hospital environment and concern ourselves with the health and well-being of the whole family" (p. 646).

In recent years, a small but growing interest in siblings' responses to a child's illness has emerged (Knafl, 1982). However, little has been done by way of research on the effects of illness on a child or his/her sibling, but problems are known to exist (Issner, 1972). Parents and the sick child have often been studied, but within the family the effects on the well siblings of chronically or terminally ill children are less well-known (Lavigne & Ryan, 1979).

Futterman and Hoffman (1973) contended that when a family is upset and stressed about an ill child, ramifications occur throughout the whole family system, which, in turn, cause shifts in the way family members relate. Thus, it not only has an impact on the child's behavior, but each family member is "at risk" for emotional problems.

When a child is hospitalized, emotional care is generally given to the patient and to the parents, but siblings are often neglected (Everson, 1977; Ponder, 1975; Taylor, 1980). Needs of hospitalized children have been acknowledged, but few programs exist for the entire family even though pediatric nurses have long realized a need for them (Everson, 1977).

Koocher and O'Malley (1981), speaking of childhood cancer, stated:

> Siblings should clearly not be neglected by the treatment team during the course of a child's illness. They should be seen as an integral part of a whole family approach to treatment and acknowledged as important participants in the family's life throughout the illness (p. 111).

> Information is needed on changes occurring within the family, between family members and with peers that affect the siblings. Answers to such questions are essential to the development of "informed" approaches to helping families cope with illness and handicaps (Lavigne & Ryan, 1979, p. 626).

"Little has been written in the literature regarding sibling adjustment (to cancer) and that which has been written is largely anecdotal and case study related" (Spinetta, 1981a, p. 15).

The psychosocial literature on childhood cancer deduces that healthy siblings may be vulnerable to stress (Binger, 1973; Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Cairns, Clark, Smith, & Lansky, 1979; Kaplan, Grobstein, & Smith, 1976). It seems for the most part researchers have relied on parental report for data on siblings (Binger et al., 1969; Kaplan, Smith, Grobstein, & Fischman, 1973; Taylor, 1980).

According to Gayton, Friedman, Tavormina, and Tucker (1977), most investigations have produced inconclusive or conflicting results as to the effects on the well sibling of the illness of a brother or sister. Small numbers of subjects and subjective measurements may reflect methodologic difficulties. Also, problems in the use of suitable controls may produce inconsistent results (Vance, Fazan, Satterwhite, & Pless, 1980).

The assumption that chronic illness in a child has negative effects on family members (Anthony, 1970; Talbot & Howell, 1971) was substantiated mainly on case histories (Apley, Barbour, & Westmacott, 1967) or on studies without controls (McMichael, 1971).

Most studies have focused on the child or mother, and only occasionally have fathers been part of the research data (Tew, Payne, & Laurence, 1974). As mentioned previously, "Much research has been conducted on children with cancer and their parents; however, there is a paucity of well-designed research on siblings of children with cancer" (Spinetta, 1981b, p. 133).

Knafl (1982) wrote:

> The literature has focused on how nonhospitalized children perceive their siblings' illness or their psychological response to it. The emphasis has been on studying siblings of either

> chronically or seriously ill children. Very little is known about how siblings respond to the more usual short-term hospitalization of a brother or sister for a relatively minor condition. In addition, very little is known about the role of siblings in the family's overall adjustment to hospitalization (p. 14).

Much of the research done on siblings of chronically ill children has been done by interviewing parents rather than siblings (Harder & Bowditch, 1982). "The few studies in which siblings of chronically ill children were tested themselves had conflicting results" (Harder & Bowditch, 1982, p. 116).

All of the above studies seem to indicate that research on siblings of the hospitalized and ill child should be an imperative and necessary part of preventive medicine and health care for all children.

Statement of the Problem

It has been shown that the well sibling of a hospitalized child has seldom been studied. Most information available about a well siblings' perceptions of having a brother or sister hospitalized has been obtained from parent report data. Consequently, the main purpose of the present study is to investigate the perceptions of both the well siblings and parents concerning an ill child's hospitalization and possible similarities and discrepancies. After researching the literature, the following major family areas were identified for study: (a) family maintenance; (b) family relationships; (c) family communication; (d) health attitudes; and (e) perceptions of siblings, parents, and the hospitalized children.

Hypotheses

To sharpen the focus and to further clarify the study, the following null hypotheses were formulated:

I. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family maintenance issues.

a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on household issues.

b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on caregiving issues.

c. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family tasks.

II. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family relationships.

a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the affection shown in the family.

b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship.

c. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship with the hospitalized child.

d. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship with the well sibling.

III. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family communication.

IV. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the health attitudes of the well sibling.

V. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family members.

a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the well siblings' perception of his/her parents.

b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the well siblings' perception of him/herself.

c. There is no agreement retrospectively between family members' perceptions concerning what the relationship between the well sibling and the hospitalized child was previous to hospitalization.

Limitations of This Study

Because of the small relatively homogeneous sample, the reader is cautioned about conclusions inferred from this study. It is not intended that the findings be applicable to any population other than that from which the sample was drawn, and inferences concerning other possible samples can only be speculation. These families in this study were interested in helping the health care profession and volunteered to participate in this study.

Organization of the Study

The Introduction provides background on this study and presents the need for well sibling research.

The Review of Literature examines the research on parents of hospitalized and ill children, the hospitalized and ill children themselves, well siblings of hospitalized and ill children, families of hospitalized and ill children, and ameliorative efforts for all of the above.

The Methodology describes the subjects studied, the instruments used, the methodological procedures followed, and the statistical treatments selected.

The Findings section presents the results of this investigation.

The Summary, Ancillary Findings and Discussion, and Recommendations section summarizes the study and discusses the results. Implications for further research are also cited.

REVIEW OF LITERATURE

In order to determine the impact the hospitalization of a child has on the parents and the well siblings, the investigator examined the literature pertaining to how family members were affected by a child's hospitalization. The purpose of this review of literature is to provide background information on hospitalized and ill children, their parents, and siblings, and the family reaction to such exposure as well as the ameliorative efforts for all concerned. Therefore, the literature is reviewed under the following subheadings: (a) parents of hospitalized and ill children; (b) hospitalized and ill children; (c) well siblings of hospitalized and ill children; (d) families of hospitalized and ill children; and (e) ameliorative efforts.

Parents of Hospitalized and Ill Children

Research findings suggest that there is considerable upheaval in the lives of parents when children are hospitalized. The parents have been studied from the perspectives of diagnosis and stages of illness, overprotectiveness, anxieties and fears, marriage relationships, coping methods, treatment failure and death, and sources of emotional support. Each of these perspectives will be examined in this review.

Diagnosis and Onset of Illness

Stress, emotional, and adjustment problems have often been seen in parents of children who are pediatric patients (Cummings, Bayley, & Rie, 1966; McAllister, Butler, & Lei, 1973; Turk, 1964).

> To parents, however, illness, in any form, is an obstacle to the development of the child. The implication for them, of course, is that somehow they failed, through either neglect, ignorance, or heredity; and when they must surrender the care of their child to others they are admitting their guilt or their own physical or psychological inadequacy (Issner, 1972, p. 10).

When the diagnosis is made of cancer, some parents may react with guilt or anxiety, while others may exhibit emotional withdrawal, somatic complaints, shock, feelings of alienation, and hostility toward hospital staff (Binger et al., 1969; Chodoff, Friedman, & Hamburg, 1964; Dargeon, 1960; Friedman, Chodoff, Mason, & Hamburg, 1963; Johnson & Miller, 1975; Johnson, Rudolph, & Hartmann, 1979; Knudson & Natterson, 1960). Shock, disbelief, and feelings of numbness at the time of diagnosis were reported by Stehbens and Lascari (1974). Similar findings were suggested by Hughes (1976) along with anger and acceptance. The most frequent parental reaction patterns identified included guilt (Zuk, 1959), acceptance (Miller, 1968), and chronic sorrow (Olshansky, 1960).

Orbach, Sutherland, and Bozeman (1955) explained that the period immediately following diagnosis is a time of intense parental anxiety which may be manifested in failure to comprehend information, acute feelings of personal responsibility for the illness, fears of separation, hostility toward the medical staff, and disruption of functioning. Kaplan, Smith, Grobstein, and Fischman (1973) also found that parents who refuse to accept the diagnosis sometimes show overt and strong hostility toward members of the medical staff.

Hughes (1976) mentioned that each parent initially rejects the diagnosis of a serious or chronic disease in his/her child. Parents also inevitably felt guilt (Friedman et al., 1963; Hughes, 1976).

From a collection of sources, Battle (1975) summarized the behavior of the parents and the resultant feelings about the chronically ill child. Parents responded with feelings of protection and/or revulsion when learning their child was chronically ill. Parents also experienced feelings of inadequacy, bereavement, shock, guilt, and embarrassment.

In a two-year investigation of 46 parents who were under chronic psychological stress due to the fact that their children had a fatal illness (mostly leukemia), Chodoff et al. (1964) found that each parent reacted to stress in an individual manner. Chodoff and associates noted that, as a whole, the subjects passed through a predictable sequence of events as they adapted to the situation. The initial diagnosis resulted in shock and disbelief. Once the child was admitted to the hospital, however, a characteristic split between an intellectual acceptance and an emotional nonacceptance was seen. Parents needed to search for meaning and go through anticipatory mourning. Similar findings have been cited in Bozeman, Orbach, and Sutherland (1955), Futterman and Hoffman (1973), and Knudson and Natterson (1960).

Heffron, Bommelaere, and Masters (1973) mentioned that children having acute leukemia whose parents attended weekly group meetings went through the five characteristic Kübler-Ross (1970) stages: denial, anger, bargaining, depression, and acceptance. Kartha and Ertel (1976), Knapp and Hansen (1973), and Smith and Schneider (1969) reported parents going through similar stages.

Friedman et al. (1963) studied 46 subjects who represented one or both parents of 27 children with neoplastic disease over a two-year period.

Parents' initial reaction of shock to the diagnosis was followed immediately by self-blame. Then many parents went through a phase where they sought out all information about the disease. Bozeman et al. (1955) and Natterson and Knudson (1960), who worked with fatally ill children and their families, have also described the need of parents to begin intensive questioning after the initial diagnosis. Another characteristic Friedman et al. (1963) found was that parents had difficulty leaving the child. Treatment procedures were painful for child and parent alike, but the parents began using coping behaviors. They also searched for meaning. Anticipatory grief was a common process parents experienced, but they finally resigned themselves to the inevitable outcome.

Overprotectiveness

A common parental reaction was overprotectiveness toward the ill child. Overprotectiveness may hinder treatment and also be accompanied by pity (Hughes, 1976). Boone and Hartman (1972) talked about the benevolent overreaction which includes overprotection, overindulgence, and permissiveness that begins when parents realize their child is handicapped in some way. Boone and Hartman warned that this is not always helpful to the child.

Friedman et al. (1963) studied parents who had children in remission from neoplastic disease and found that discipline was a problem. These parents tended to overindulge and overprotect their child. Common mistakes in overindulgence and overgenerosity toward the sick child can aggravate sibling jealousy (Cairns, Clark, Smith, & Lansky, 1979; Johnson et al., 1979; Kagen-Goodheart, 1977). If a child is overprotected, this may foster regression and acting out behaviors (Johnson et al., 1979; Kagen-Goodheart, 1977; Van Eys, 1977). A balance between encouragement and limit setting within the family was stressed.

In general, it was found that parents try to shield the sick child from a total awareness of his/her illness and the possibility of the fatal outcome (Binger et al., 1969; Friedman et al., 1963). Binger et al. (1969) found that the loneliest children were those children who were aware of the diagnosis of cancer but at the same time realized their parents did not wish them to know. When parents tended to protect children from concerns of cancer, the older ill children tended to protect parents.

Anxiety and Fears

Much evidence in the literature suggested that parents, especially mothers, may suffer extreme distress over their child's illness, hospitalization, and surgery (Belmont, 1970; Burling & Collipp, 1969; Duffy, 1972; Gofman, Buckman, & Schade, 1957; Mechanic, 1964). Mechanic (1964) found that children seemed to take their cues in responding to illness from their mother's response to illness both in herself and in her child. Langford (1961) mentioned the hospitalized child may be genuinely distressed due to fear and anxiety communicated from the mother. Hughes (1976) cautioned that parental adjustment and, in turn, child adjustment depend on parental attitudes and the emotional balance parents had prior to their child's illness.

A study done by Adams and Sarason (1963) examined the relationship of anxiety between well adolescents and their parents. The following four measures were used for both parents and children: Test Anxiety Scale; Need for Achievement Scale; Lack of Protection Scale of the Autobiographical Survey; and Bendig's brief version of the Taylor Manifest Anxiety Scale. Significant positive correlations on all four scales were found between mothers and daughters. For mothers and sons, two of the four correlations reached significance. Anxiety scores for mothers and children related more strongly than fathers' scores. Thus, the authors concluded that anxiety may be studied meaningfully in the context of the family.

Asen-Rudbarg Vardaro (1978), using the concept of anxiety developed by Cattell and Scheier (1961) and Spielberger (1972), which divides anxiety into state anxiety and trait anxiety, tested to see if there was significant relationship between the parents' anxiety and the child's anxiety. The instruments used were: a urine test for 17-hydroxycoricosteroid given to both mother and child (17-OHCS); the State Trait Anxiety Inventory Self Evaluation Questionnaire (STAI) which was given to the mother; and the Prehospital Behavior Questionnaire (PBQ) which the mother filled out on her child. There were 18 mothers and 18 children ranging in age from 36 to 66 months who were admitted to the hospital for hernia repair. Results indicated a highly significant positive correlation between the mother's anxiety about her preschool child's hospitalization and the child's 17-OHCS. The mother's 17-OHCS with the child's 17-OHCS was $r = .8699$ ($p<.001$) and the mother's STAI with the child's 17-OHCS was $r = .9334$ ($p<.001$). A conclusion drawn by Asen-Rudbarg Vardaro was that since these children had no previous hospitalization or any formalized preparation for such, the anxiety these children expressed could have been transmitted from the mother. There also was a significantly high correlation $r = .9424$ ($p<.001$) between the mother's STAI and her 17-OHCS.

A nurse researcher asked 25 mothers to discuss the hospital experience of their child. All mothers felt some degree of fear, anxiety, or uneasiness. Eighteen of the 25 mothers mentioned a specific incident that frightened either them or their husbands. Lack of information was repeatedly stressed as a major cause of worry. Guilt about the child's illness and blaming themselves for not being able to prevent it were common themes in the mothers' responses (Freiberg, 1972).

Over 300 mothers whose under five-year-old children had been admitted to one of seven South Wales hospitals were interviewed (Robinson, 1968). Results indicated that mothers who had a high level of fear of being hospitalized themselves were more concerned about their child's being frightened of hospitalization than they were of the child's actual illness. The more frightened the mother was of being hospitalized herself, the greater was her desire to take advantage of unlimited visiting with the hospitalized child. However, there seemed to be a break with intention and action because with an increase in the mother's personal fear, there was a decrease in time she visited. Also, as the mother's personal fear increased, there was a gradual decrease of mothers who contacted the hospital staff. Thus, Robinson concluded that parents' fears or emotional tensions are a major problem and should be recognized when admitting a child to the hospital.

Other studies had similar conclusions. Parental response to the child's injuries had a great impact on the child's behavior (Pearson, 1941). If children perceived that their parents were anxious and upset, their own fears were compounded. Parents' reactions to the child's hospitalization affected the child's reaction (Quinton & Rutter, 1976).

Nagera (1978) suggested that many parents who become difficult and irrational when a child needs surgery or is hospitalized often have suffered negative hospital experiences themselves. Such parents can unconsciously influence their child by transmitting their unconscious anxieties.

Marriage Relationships

Several authors have reported marital problems and lack of support from a spouse in families when a child has a fatal illness (Binger et al., 1969; Hamovitch, 1964; Heffron et al., 1973; Kaplan et al., 1973; Murstein, 1960). Tew, Laurence, Payne, and Rawnsley (1977) reported on the marital stability of 142 families with a child born between 1964 and 1966 who had neural tube malformation (mostly spina bifida). Included in this sample which was obtained in 1976 were 56 families who had a surviving spina bifida child. The divorce rate for the families with a surviving child was nine times higher than the local population, while the divorce rate was three times higher for families where the spina bifida child died. Tew et al. (1977) then concluded that a handicapped child added a great strain to marriage. Grossman (1975) suggested that when parents have a child with cystic fibrosis, the couple's marriage may be under considerable strain with the couple having little time to spend together and, perhaps, one parent blames the other for the child's disease.

Problems such as parents blaming each other for the child's illness or one parent accepting the diagnosis and the other parent refusing to accept it have arisen (Hughes, 1976). Sometimes parents have selected different coping styles and thus made it difficult to support each other (Kaplan et al., 1973). Sourkes (1977) explained that parents most likely will be at varying stages of emotional response at different times and thus will not be going through the same coping stage simultaneously. Easson (1970) made it known that with all the stresses of transportation, finances, and coping with the child's return, parents need to decide to sort out what is most important, or they may build up resentment toward each other. Kagen-Goodheart (1977) emphasized the stresses placed on a parent's marriage when a child is going through treatment and suggested that parents spend time alone with each other to ascertain the most meaningful aspects of their marriage.

In their extensive research of families who had children that survived cancer, Koocher and O'Malley (1981) found at the time of diagnosis 112 parents were married, 2 were separated, and 4 were divorced, and the status of one couple was unknown. At the time of the research interview, some 5 to 20 years after diagnosis, 99 were still married, 2 were separated, 10 were divorced, and 3 families had at least one deceased parent. Thus, they concluded that marriages tended to remain stable in families where a child had cancer. Lansky, Cairns, Hassanein, Wehr, and Lowman (1978) studied the marital status of parents of 191 children who were treated for cancer. Contrary to a prediction of a high divorce rate for parents of children with cancer, the researchers found the divorce rate similar to the population at large. However, Lansky et al. (1978), using the Arnold sign indicator analysis of the Minnesota Multiphasic Personality Inventory (MMPI) to measure marital stress in 38 couples whose children had cancer, reported that the couples of children with cancer reported more stress than 23 couples of children with hemophilia. Both of these groups had more stress though than a normal control group.

In studying 19 families where a child, ages 15-22 years, had a traumatic spinal cord injury, Cleveland (1980) found that parents' post-injury marital relationship was significantly affected. The mother's physical involvement with the injured child resulted in a decreased amount of time spent with her husband. The researcher also reported the mother's emotional involvement with the injured child decreased her ability to take an active interest in the marriage. These families also experienced husbands' anger at wives and ongoing tension between them in terms of the mothers' protectiveness toward the injured child. In general, both parents said their marriages had neither been harmed or improved because of their child's accident.

Lascari and Stehbens (1973) reported that in some cases families became more united and remained closer together when having to face a mutual problem. In 1974, the same authors studied 20 families of children who had died of leukemia. The majority of the families felt the illness had no adverse effect on marriage while one-third felt it had made their marriage stronger. Futterman and Hoffman (1973) discovered that even though the experience faced by the parents may be extremely painful, it is often growth producing.

Estrangement from marital partners is not uncommon when a family is coping with the potentially fatal illness of a child. Several researchers such as Binger et al. (1969), Bozeman et al. (1955), Kartha and Ertel (1976), and Stehbens and Lascari (1974) described a tendency in fathers to withdraw into their jobs and use their work as an escape from the pain of their child's illness.

Hughes (1976) advocated that physicians need to know something about the personal relationships between parents. He noted that marital discord may have been present before the illness, but the burden of a chronically ill child may just accentuate the difficulties. Similarly, Hamovitch (1964) suggested that the quality of the marriage relationship before a diagnosis of cancer is an important factor in how well parents adjust to the crisis. If the family structure is already weak, the stress associated with a child's illness may severely tax it.

Coping Methods

According to Friedman et al. (1963), "coping behavior is a term that has been used to denote all the mechanisms utilized by an individual and to meet a significant threat to his psychological stability and to enable him to function effectively" (p. 616). To Cohen (1962), the family's adjustment to their child's illness was related to its customary pattern of dealing with stress. However, Kaplan et al. (1973) warned, "For any serious illness coping demands and responses are not static but change as the medical treatment of the illness changes" (p. 62).

Friedman et al. (1963) explained:

> Coping mechanisms observed in parents should be viewed in terms of how much behaviors contribute or interfere with meeting the needs of the ill child and the family members, yet not neglect to appreciate the protective function which such behavior has in keeping anxiety and depression within tolerable limits (p. 624).

Kaplan (1968) suggested that if parents fail to cope successfully after the initial diagnosis, it often interferes with satisfactory coping by the rest of the family. Mabry (1964) noted that it is not infrequent to find families having difficulty coordinating the goals of medicine with those of the family. Some families may appear either indifferent or uncooperative because the therapeutic regimen may conflict with behavior patterns and attitudes at home.

Friedman et al. (1963) found parents often used intellectualization, denial, and motor activity as coping mechanisms to buffer the impact of learning their child had a fatal illness. Battle (1975), gathering data from several authors (Howell, 1973; Maginnis, 1968; Mattson, 1972; Solnit & Stark, 1962), suggested several factors that seem to significantly improve a family's ability to cope with a child's chronic illness. They are as follows: a good relationship between the mother and maternal grandmother; a strong marital relationship; birth order other than the first; access to a circle of understanding friends; an opportunity for recreation both with and without family members; an ability to plan and prepare household management matters ahead of time; a dwelling location that is convenient to shopping, schools, and transportation; a deep religious faith; an opportunity to reach out and help others; and being told of the child's disability as early as possible (p. 528).

Lindsay and MacCarthy (1974) suggested that parents' loss of confidence in their parenting skills, once their child becomes ill or hospitalized, is sometimes generalized in feelings of inadequacy with other siblings as well.

Treatment Failure and Death

Many parents have pointed to the time their child had a relapse or recurrence of cancer as the most stressful and difficult time of the child's illness (Koch, Hermann, & Donaldson, 1974). Lascari and Stehbens (1973) studied parents of 20 deceased children who had leukemia. Most parents could accept the reality of the disease and had no major problems after the child's death. However, it took two parents one to two years for their mood to return to normal while one man still had crying spells two and one-half years later.

Chodoff et al. (1964) stated that most families prepared for the death of a child and were able to cope adequately without breaking down. Binger et al. (1969) reported the parents of 10 children felt both a sense of relief and grief when their ill child died.

Other literature presented further reactions concerning the death of a child. Once the parents receive the diagnosis of a terminal illness, they begin to grieve (Bozeman et al., 1955; Futterman & Hoffman, 1973). Parents often are shocked and angry, and at times the need to deny is so strong they do not hear what the health care team tells them (Barton, Flexner, Van Eys, & Scott, 1972). It seems for some parents there is an optimal level of keeping anxiety and depression within tolerable limits by maintaining a certain level of denial or hope (Friedman et al., 1963). An indicator of whether or not parents are making successful adaptation is their ability to continue caring for the child (Tropauer, Franz, & Dilgard, 1970).

Parents of a dying child can help each other, especially when they realize and accept the fact that they each may experience the child's dying process differently (Kennell & Klaus, 1976). Gyulay (1975) suggested that fathers are often "forgotten grievers." They may feel rejected and then withdraw or begin working longer. Mothers tend to accept the inevitable before fathers because they face daily crises with the child. Rarely are parents at the same grieving stage. Fathers frequently have more difficulty in expressing their grief and often absent themselves from the experience to avoid pain (Binger et al., 1969).

Sources of Emotional Support

Parents appear to need support when they have a hospitalized child. The importance of using relationships for emotional support is an important and effective method of coping for parents of children with cancer (Bozeman et al., 1955; Futterman & Hoffman, 1973; Kaplan et al., 1973). A study done by Kaplan et al. (1973) found when a healthy child becomes ill, family members need to find support and comfort in each other. Sussman and Burchinal (1962) explained that related kin provided a major form of assistance or help during illness. No significant differences in the amount of help given or received during an illness of a family member was found between the social status groups. In their interviews with parents, Koocher and O'Malley (1981) found that family members, their own children, and the courage of their cancerous child gave them support to keep going. Religion for some parents was a comfort and offered support according to Friedman et al. (1963).

Parents of children with cancer often mentioned that their primary source of support in helping to cope with their child's illness had been their spouse (Binger et al., 1969; Bozeman et al., 1955; Hamovitch, 1964). Koocher and O'Malley (1981) agreed with this position. They revealed that relationships with family members, especially the spouse, are usually the most important source of support and, thus, open communication is vital. Clarke-Stewart (1973) contended the support of the father to the mother in her interaction with the hospitalized child most likely affects how the mother is able to help the child with the hospitalization experience. Mothers of the hospitalized children said that their spouses helped in meeting some of the practical problems such as transportation and care of other children. Several fathers initiated diversions and insisted that their wives participate in activities and maintain social contacts (Bozeman et al., 1955).

In reporting their clinical impressions of 46 parents of children with cancer, Friedman and associates (1963) related that even though friends and relatives sometimes aggravated the parents' distress, they also provided significant emotional support in the form of listening and offering assistance. Bozeman et al. (1955), in their study of mothers of hospitalized children, noted that people who offered emotional support were sensitive to the mother's need to talk or not to talk about her child's illness;

listened to their feelings; reassured them about their ability to function; showed a willingness to help; and were concerned about the mother's own well being. However, not all family members (Friedman et al., 1963) or friends (Binger et al., 1969) or even religious affiliations (Binger et al., 1969; Friedman et al., 1963) were able to satisfy parents' needs through the reliance upon them. Bozeman et al. (1955) reported that siblings, especially sisters, husbands, and friends, provided emotional support to mothers. Maternal grandmothers seemed to provide more tangible services than emotional support to the mothers.

A major source of support was other parents who had children with similar problems (Friedman et al., 1963). The section on parent groups contains more information on this aspect. The child's physician is still another major source of support to parents according to Friedman et al. (1963) and Natterson and Knudson (1960).

Clapp (1976) cited the Candlelighters and PALMS (Parents Against Leukemia and Malignancies), and similar parent-founded groups, as sources of both physical and emotional support. Housing, temporary childcare for siblings, meals, and opportunity to share experiences with members are some services provided by these groups.

In summary, the hospitalization of a child appears to precipitate adverse reactions in parents. However, some positive coping methods have been reported. Findings in this area are not always consistent. This was especially noted in marriage relationships. A review of the research indicated that the following factors are involved with parents' reactions: diagnosis and stages of child's illness; over-protectiveness; anxieties and fears; marriage relationships; coping methods; treatment failure and death; and sources of emotional support.

Hospitalized and Ill Children

Studies showed that hospitalized or ill children experience considerable stress. Separation anxieties, inhospital behaviors, self-esteem changes, posthospital behaviors, concerns about treatment failure, and death have been studied. Results of research in these areas are reviewed here.

Stress of Hospitalization and Illness

Hospitalization is a stressful experience for children (Hodapp, 1982; Menke, 1981; Skipper & Leonard, 1968). Hughes (1976), in a speech to the American Medical Association, suggested:

> one might list the basic emotional needs of children (and adults) as follows: (1) love and affection; (2) security; (3) acceptance as an individual; (4) self-respect; (5) achievement; (6) recognition; (7) independence; and (8) authority or discipline. Knowing how these basic needs are threatened by a chronic disease or handicap helps the physician in his efforts to minimize the emotional impact (p. 1202).

Thus, Hughes urged that the approach to a chronically ill child should be thoroughly comprehensive and should help the child to achieve, insofar as possible, his/her maximum potential mentally, emotionally, physically, and socially. Hughes believed that a physician doing a comprehensive analysis of a child with a chronic disease or handicap should take the following factors into consideration:

> (1) nature of the chronic disease or handicap; (2) age of the child at the onset of the disease; (3) parental attitudes and emotional balance; (4) emotional adjustment of the child at the

> onset of the disease; (5) threats to the basic emotional needs of the child and how they are met; and (6) availability of special facilities and programs (p. 1203).

Clapp (1976) explained that a child diagnosed as having cancer was considered terminally ill in the 1950s. Advancements in diagnosis and treatment, however, have brought increasing survival and sometimes have produced a cure for childhood cancer. Now cancer has become a chronic disease with the outcome unknown. Li, Casady, and Jaffe (1975) wrote that though cancer is the second leading cause of death in children under 15 years of age, survival rates have been improved with chemotherapy, surgery, and radiation.

From a study done in 1978, Nagera concluded that the length of time hospitalized and the possible severity and length of the reactions could be determined by age and level of development of the child, whether there were indications of previous psychiatric problems, and if the child had the capacity to be separated from the mother and accept a mother substitute. The youngest child had the greatest risk. The author also felt that some exploration should be done to see if children could express themselves verbally so that anxieties, fantasies, and misconceptions could be communicated and some determination made of the child's reaction to facing new situations, particularly those inducing anxiety.

The exact nature of the threat from hospitalization and surgery is due to factors such as developmental level of the child, age, prior similar experiences, and the amount of information and support received from others (Visintainer & Wolfer, 1975). These same authors found that these threats could be classified into five categories:

> (1) physical harm or bodily injury in the form of discomfort, pain, mutilation, or death; (2) separation from parents and the absence of trusted adults (especially for preschool children); (3) the strange, unknown, and the possibility of surprise; (4) uncertainty about limits and expected "acceptable" behavior; and (5) relative loss of control, autonomy, and competence (p. 187).

However, Menke (1981) believed that few systematic studies of emotional effects of hospitalization had been conducted. Cassell (1965) suggested that most of the studies concluded that hospitalization and its procedures were likely to have a serious affect on later psychological adjustment but was concerned about the methodology used in most studies.

"Strong statements describing the negative consequences of hospitalization were already appearing in the literature 30 to 40 years ago" (King & Ziegler, 1981, p. 20). A study by Edleston (1943) concluded that the younger the hospital patient, the more profound the disturbance.

Langford (1961) indicated that there is evidence that the distress of illness, hospitalization, and surgery may be magnified for children. When children do not understand what will happen to them in the hospital and believe they will lose control or that their body will be harmed, the hospital experience becomes very stressful to them (Bellack, 1974; Prugh, Staub, Sands, Kirschbaum, and Lenihan, 1953).

Dombro (1970) pointed out that the biggest problem for the child patient is the fear and apprehension experienced prior to an operation. On the other hand, Haller, Dolan, Dombro, Graff, and Talbert (1966) found that a child who is going to have corrective heart surgery may have much less anxiety than a child who is going to experience a dental extraction. Work done by Haller (1967) convinced the author that for an operation to be truly successful, the child must be no worse for the emotional experience.

While Vernon, Schulman, and Foley (1966) explained that hospitalization is a psychologically upsetting experience for children, Prugh (1965) contended that predetermined factors such as the child's past experience with illness, hospitalization, his/her age or level of development, and the child's attitudes towards doctors and nurses will determine how the child copes with pain and anxiety.

Murphy (1961) spoke of great stress in children when they are injured badly enough to require emergency services. Murphy (1961) also suggested that since resources for the child to deal with stress and to think logically are limited, the child may often resort to fantasy in coping with pain and fear.

Stocking, Rothney, Grosser, and Goodwin (1972) studied children admitted to pediatric hospitals. Eighty randomly selected children were interviewed by a psychiatrist within 48 hours of admission, and six months after discharge a home visit was made. Stocking et al. (1972) reported 63.7% of the children needed psychiatric consultation; however, the ward staff requested consultation for only 11.3%.

Although few studies used controls, Stott (1957) and Woodward (1959) used nonhospitalized controls. Both were studied retrospectively, but each found that hospitalization and illness were traumatic experiences.

In a comprehensive review of the literature, Vernon, Foley, Sipowicz, and Schulman (1965) concerned themselves with the psychological responses of children to the hospitalization experience. Four variables concerning hospital upset that were cited most often were unfamiliarity with the hospital setting, separation from parents, age, and prehospitalization personality.

In a 1982 study, Hodapp found that the hospitalized child's life is disrupted, physical pain may be felt, and there is interference in cognitive achievements. Further, the child experiences maternal, sensory, and experiential deprivation in the hospital. Other family members also have their lives disrupted. However, Hodapp (1982) concluded that hospitalization rarely caused long-term emotional problems.

Separation anxiety in young children. Ainsworth (1973), Bowlby (1960, 1966, 1969), and Casler (1961) documented the adverse effects of separating children from their mothers during the critical ages of 14 to 36 months. One manifestation of separation anxiety experienced after a child is hospitalized is regression to earlier behaviors. Supportive work with parents can help them cope with these frustrating and confusing behaviors (Prugh et al., 1953).

Droske (1978) found that children upon discharge, ages 18 to 36 months, characteristically reacted in wanting more attention from their mothers, increased their intensity in protest to temporary separation from her, and experienced more sleep disturbances.

Groups of hospitalized children, ages 14 to 36 months, were compared by Branstetter (1969) to see whether the reaction to separation was due to the child's attachment to the mother, to the stress of the hospital experience, to a need deprivation, or to lack of mothering. Three groups with 10 subjects in each group were studied. They were as follows: a group with mother present day and night; a group with warm and caregiving substitute mother present during the child's waking hours; and a group with the mother absent. On the second, third, fifth, and seventh day of hospitalization, the children were observed for 15 minutes twice a day. The children in the mother present and substitute mother groups played more, cried less, were less withdrawn, and were generally happier than children in the mother absent group. Branstetter concluded:

> the emotional stress seen in hospitalized children in this age group originates from need deprivation--a lack of mothering care rather than from anxiety per se due to the loss of the mother as a special irreplaceable object of love (p. 96).

Inhospital behaviors. Hospitalized school-age children may respond to stressful situations by crying, regressing in behavior, being irritable, and struggling against treatments or tests (Klinzing & Klinzing, 1977; Prugh et al., 1953; Vernon, Foley, & Schulman, 1967). Bellack (1974) reported nonverbal responses to fears and pain in hospitalized children as clenching teeth and tightly shutting the eyes. Medical staff may see signs of "fight-flight" syndrome (Selye, 1956) such as increased respiration, perspiration, pulse rate, and pallor.

Dombro (1970) believed that a child's hospitalization is a major emotional experience which could range from a satisfying experience to a very frustrating experience to a completely incomprehensible experience which produces new fears for the child.

With hospitalization, the two main outcomes for children were depression and anger (Grossman, 1975). If they had few, if any, opportunities to express feelings and communicate fears, the children became preoccupied with themes of death and fear of separation.

Douglas (1975) and Prugh et al. (1953) found that short-term effects of hospitalization seem to be dependent upon age, with children under 5 years of age suffering more crying, sleep disorders, and bladder problems than older children.

Using systolic blood pressure as a stress indicator, Clayton and Hughes (1952) realized that of 96 children, ages 2-12 years, 53.0% had elevated blood pressure at admission.

In Friedman et al. (1963), parents reported that their children who had neoplastic disease openly rejected their parents because the parents could not prevent painful procedures. Instead of asking parents, the children rapidly transferred authority to the doctors and nurses and would ask them for permission to play or deviate from their diet. Also, cancer patients have been reported as manipulative and difficult to discipline (Heffron et al., 1973).

Several studies emphasized the importance of children's emotional states before the admission as a factor in later disturbances (Brain & Maclay, 1968; Douglas, 1975; Prugh et al., 1953; Vernon et al., 1965).

Another factor that may be related to children's emotional problems is unnecessary hospitalization (Stocking et al., 1972). In that research, the psychiatrist felt 30.0% of the 80 child subjects did not need hospitalization and that it was disadvantageous to them. The pediatrician, however, felt that only 12.5% did not require hospitalization and concurred with it being disadvantageous. In the group of children judged by the psychiatrist to be hospitalized unnecessarily, 24 of the 27 showed signs of emotional disturbance. The researchers concluded that too often hospitalization is used by parents and doctors to deny the child's emotional disturbance rather than to seek help at a mental health facility.

Over a period of two years, Danilowicz and Gabriel (1971) observed 67 children who had cardiac surgery. Immediately after surgery, cataloging responses began. Of the sample, most patients showed anxiety, withdrawal, and restlessness. Ten children were overtly angry and combative during intensive care while seven were complacent. However, the researchers cautioned that emotional reactions to hospitalization are normal, and only extreme overreactions should be seen as abnormal.

Another study, conflicting with most of the above mentioned, was done by Shrand (1965) who asked mothers to complete a questionnaire about children they cared for at home rather than having them hospitalized. Unfortunately, there was no control group. He concluded that even though the children did not exhibit despair and detachment, they had problems similar to those of hospitalized children. Thus, the question arises as to whether the illness or the hospitalization increases negative behaviors in children.

King and Ziegler (1981) concluded in their review that:

> (1) Hospitalization does tend to have negative effects; (2) The effects appear to be greatest for children between seven months and about five years of age; (3) Illness itself appears to be disturbing; (4) Hospitalization for over a week that occurs under five years of age appears to have very long term effects; and (5) Many children are not disturbed by the hospitalization experience (pp. 22-23).

Self-esteem changes. Components of a child's daily personal interaction routine, such as teacher or peer relationships, seem to influence school age children's self-esteem (Piers & Harris, 1964; Wattenberg & Clifford, 1964). By late school age, events extraneous to their daily personal interaction routine seem to influence self-esteem. Kessler (1966) reported that situations which threaten maintaining age appropriate skills may create changes in self-esteem.

Hospitalization and surgery are examples of events which may cause regression or difficulty in maintaining age-appropriate behavior. Riffee (1981) explored whether or not there was a change in self-esteem scores of late school age children after hospitalization. The sample consisted of children, ages 9-12 years, who had no disability or terminal illness, had not experienced a family crises during the month previous to hospitalization, and had not been hospitalized one year prior to the study. Twenty-six surgical, 25 nonsurgical, and 28 nonhospitalized subjects met the criteria. The three groups were comparable in age, sex, and grade in school. Self-esteem was measured by Coopersmith's Self-Esteem Inventory on the day the child was admitted to the hospital and again one month later. Riffee (1981) found that total self-esteem scores dropped more for surgical children than nonhospitalized or nonsurgical children. The surgical group's peer/social subscale dropped more than the other two groups, and the school subscale scores of both nonsurgical and surgical children dropped more than scores of nonhospitalized children.

Goldberg (1974) found that changes in physical appearance such as hair loss, an amputation, or jaundice are great sources of distress for children. Children with visible physical defects tended to have difficulties in social adjustment both in the hospital and upon returning home.

Posthospital Behaviors

Douglas (1975) reported that hospitalization of children is common and, at times, may be associated with distress and disturbed behavior that may persist for weeks or even months. Most children, however, only show temporary distress. Douglas (1975) wanted to see if being admitted to the hospital before 5 years of age was associated with later disturbances. Adolescents in Great Britain born during the first week of March 1946 were chosen for the sample. Unexpectedly, Douglas found that one admission to a hospital for more than a week or repeated admissions before the child was 5 years of age were associated with an increase in poor reading and behavior disturbances. The author conjectured the most vulnerable children were those who were in stressful situations at home before admissions or those highly dependent on their mothers.

A study by Quinton and Rutter (1976) confirmed Douglas' (1975) that a single hospital admission of up to a week or less does not seem to increase the risk for later disturbances. Repeated or prolonged stays before 5 years of age, however, seemed to have long-term effects. Young children, from low socioeconomic status, broken or overcrowded homes, and poor prehospital adjustment may be more vulnerable to posthospital emotional problems.

After their child's hospitalization, 25 mothers in Freiberg's (1972) study reported their children were not only frightened and unhappy in the hospital but had difficulty in recuperating from the hospital experience and illness. Fourteen of 16 children below age 5 years and 6 of 9 children ages 5 to 9 years seemed to come home displaying newly acquired negative behaviors.

Posthospitalization behaviors such as nightmares, verbalization and sound withdrawal, avoidance of sports, and resistance to completing schoolwork have been found by Prugh et al. (1953) and Vernon et al. (1965). Kessler (1966) and Langford (1961) decided that children who have had surgery are threatened by their belief that they can no longer actively compete as capably as their nonsurgical counterparts. Langford (1961) also said that the hospitalized child worries about being absent from school.

Koocher and O'Malley (1981), in their study of 117 patients and their families, stated:

> survivors of childhood cancer are at a substantially greater psychological risk than are the survivors of other chronic, but not life threatening, childhood illnesses. This tendency is reflected both in our own observations of their adjustment during personal interviews and in their self-descriptive responses to objective measures of anxiety and self satisfaction (p. 72).

Using a standardized and semistructured psychiatric interview, the researchers also found that approximately half of the subjects had some psychiatric symptoms that ranged from mild to severe. The majority who had psychiatric symptoms, however, were only mildly affected.

Another problem for children with cancer is that they often have misgivings about reentering the community of family, peers, and school (Kagen-Goodheart, 1977). Children need help in facing the reentry process and in verbalizing their fears. Without this help, children may become withdrawn, isolated from peers, and regress to a dependent state (Adams, 1976).

Vernon et al. (1966) examined changes in behavior of 387 children who had been hospitalized. Parents filled out a questionnaire one week after discharge. When the questionnaire was factor analyzed, it was found that there were six types of parental responses: (a) general anxiety and regression; (b) separation anxiety; (c) sleep anxiety; (d) eating disturbance; (e) aggression; and (f) apathy and withdrawal. The findings from Vernon et al. (1966) were consistent with Schaffer and Callender's (1959) conclusions that children 6 months to 4 years of age showed the greatest negative change and that preschool age children were relatively upset which was especially evident in the area of separation anxiety.

Vernon et al. (1967), in another study of 32 subjects between ages 2 and 5 years anesthetized for tonsillectomies, found the same factors of separation anxiety, sleep anxiety, and aggression towards authority were factors which changed. Some criticism has been leveled at Vernon et al. (1966, 1967) because pre- and posttests were not done.

Davenport and Werry (1970) compared the behavior of 145 Canadian and American children, ages 1 to 15 years, undergoing minor surgery to that of a control group consisting of 95 sibling controls and 50 normal controls. The mothers were given Vernon's posthospital questionnaire when the child was admitted or, if the child was not hospitalized overnight, the mother was questioned shortly after the child had been taken to the induction room. After two weeks, each mother was contacted to complete the questionnaire again. Results indicated that there were no differences between the two national groups (Canadians and Americans) or between the two treatment groups (operated and control). Thus, Davenport and Werry's (1970) findings seem similar to Cassell's (1965) study of children undergoing heart catheterization, but they are in direct conflict with Vernon et al's. (1966,

1967) findings. Davenport and Werry concluded the similar findings to Cassell's (1965) study may have been due to short hospitalization, minimal discomfort, observer bias, and the fact that most children were beyond the most vulnerable age range of 6 months to 4 years.

Kagen-Goodheart (1977) suggested that at the beginning of outpatient care, the child may undergo adjustment problems, questioning why s(he) has to go to the hospital when his/her sibling does not. Serious resentment toward those who are healthy and active at home may occur.

Death and/or Treatment Failure

Before reaching 5 years of age, a child sees death in simple concrete terms of losing the parent's comfort or separation from parents (Morrissey, 1964; Vore, 1974). Young children think death is reversible (Adler, 1969) because of the child's immature concept of finality and causality (Piaget, 1952). During latency, the permanency of death for children begins to make an impact even though the reasoning may be incomplete (Schowalter, 1970). Death may be associated with fear and sorrow (Anthony, 1971). The adolescent realizes the finality and inevitability of death and may react in rage (Easson, 1968), or anxiety (Alexander & Adelenstein, 1958), or deal with it intellectually (Maurer, 1964). Schowalter (1970) said adolescents show more signs of depression than the other ages discussed.

Spinetta (1974), Spinetta and Maloney (1975), Spinetta, Rigler, and Karon (1973), and Waechter (1971) investigated children, ages 6 to 10 years, who were fatally ill and compared them to nonfatally ill children. In the above studies, children were rated on anxiety scales and were asked to tell stories. In all of these studies, fatally ill children were found to be more anxious when compared to nonfatally ill children or "normal" controls.

Children in Spinetta, Rigler, and Karon's (1974) study were requested to place dolls in a play patient room. This study concluded that fatally ill children placed doll figures significantly farther from a patient doll than did nonfatally ill children. Spinetta interpreted this to mean that the fatally ill child felt a growing sense of separation and isolation from decreasing contact with significant adults.

Binger and colleagues (1969) found that children over 4 years of age appeared aware of the seriousness of their illness and even anticipated their premature death.

Martinson (1976) advised home care during the terminal phase and also suggested allowing the child to die at home.

In summary, data concerning hospitalized and ill children supported the premise that hospitalization may cause psychological upset, but neither this conclusion nor the degree of disturbance is agreed upon. Separation anxiety was found to be a reality for the young child and self-esteem changes are noted in school age children. Children's reactions to impending death were variable. Inhospital and posthospital behaviors showed more emotional disturbances in some children than others. Due to studies that do not lend themselves to comparison, conclusions are not definite.

Well Siblings of Hospitalized and Ill Children

Well siblings are affected when other children in the family become ill or hospitalized. Both general characteristics of the siblings and those related to siblings whose brothers and sisters have specific illnesses have been reviewed.

General Characteristics

The child's age, sex, type of disability, and degree to which s(he) can be improved by treatment all influence the impact on the hospitalized child (Hewett, Newson, & Newson, 1970; Mattson & Gross, 1966). One might be able to assume that these same factors also affect siblings.

Studies have shown siblings to be anxious and often called upon to manage without their mothers while the ill child is hospitalized (Cain, Fast, & Erikson, 1964). Further, parents may be so absorbed in the care of the sick child that the well siblings experience resentment and rejection (McAllister et al., 1973). As parents become increasingly absent from the home due to hospital visitation, well siblings may begin to feel excluded (Everson, 1977). Often a dyad may develop within the family system to the exclusion of some family members (Spinetta, 1978). Even though there are many possible combinations of the dyad, it usually consists of the ill child and his/her mother. The structural change brought about by this dyad may leave well siblings with inadequate parental support (Gyulay, 1978). Studying the impact of childhood malignancy on well siblings, Cairns, Clark, Smith, and Lansky (1979) found siblings indeed did feel isolated from family members. In an investigation where 25 siblings of chronically ill children were interviewed, Taylor (1980) reported the greatest single effect of the illness on the well sibling was the feeling of isolation and exclusion from the family and the medical care team.

Everson (1977), a mental health nurse, found the sibling closest in age to the ill child to be the most disturbed and cited case studies about the difficulties encountered. Binger et al. (1969) interviewed parents in 20 families who had a child die from leukemia. The investigators stated:

> Each parent and sibling reacts to fatal illness individually, in a manner consistent with his own personality structure, past experience, current circumstances, and the particular meaning or special circumstances associated with the loss threatening to him (p. 418).

Siblings may be affected by marital stress that occurs in families of hospitalized children (Lansky et al., 1978). A more detailed review of this topic appears in the marriage relationships section.

Presumed effects on siblings of children with chronic illness range from jealousy, guilt, hostility, embarrassment over uncontrolled symptoms of the disease, and fear of contracting the disease one's self (Hopkins, 1973; Korsch & Barnett, 1961; McCollum, 1981; Patterson, 1973; Toch, 1974; Travis, 1978; Tropauer et al., 1970). Harder and Bowditch (1982) suggested that "medical, nursing and psychological literature contain numerous speculations and assumptions concerning the effects of chronic illness of various types on the sibling of the affected child" (p. 116).

Lavigne and Ryan (1979), using the Louisville Behavior Checklist, studied siblings of children with health problems. These children were hospitalized for pediatric hematology, cardiology problems, or plastic surgery. They found the siblings showed more signs of social withdrawal and irritability than the controls. However, siblings' adjustment problems seemed to differ in extent due to the particular illness. The children, ages 3 to 6 years, in Lavigne and Ryan's study who had siblings undergoing plastic surgery exhibited the highest levels of psychopathology. Breslau, Weitzman, and Messenger (1981), also using a control group, reported that siblings of hospitalized children with a variety of illnesses scored higher on measures of fighting and delinquency problems than the controls. However, overall impairment was not considered to be significantly different.

Mattson (1972) emphasized that a potentially fatal illness had a profound impact on siblings of the sick child. Negative behaviors are often not reported by parents until they are very severe and outside help is required. Parents also reported sibling jealousy, anger, feelings of abandonment, and guilt (Chodhoff et al., 1964; Friedman et al., 1963; Johnson et al., 1979; Kaplan et al., 1973).

In Knafl's study (1982), one or both parents from 59 families were interviewed within 24 hours of their child's admission and 4 to 6 weeks after discharge. Parents investigated had to have children, ages 5 to 12 years, hospitalized for no more than 10 days and with a prognosis of a complete recovery. Sibling participation was based on data from 59 families. Data were divided into two groups, an active and a passive group. Active groups were those families who had siblings actively participating in the adjustment to the hospitalization of a brother or sister (N = 21). Passive groups were those families in which siblings were passive participants in the adjustment process (N = 38). In the active group, parents reported older siblings took care of themselves, were expected to be substitute parents, and in some cases did housework. Some families expected siblings to do more self-care while four families expected siblings to assume new self-care responsibilities. In 6 of 21 families in the passive group, a relative or friend made a contribution to sibling care. Also, in the passive group, parents did not delegate new tasks or responsibilities to siblings but expected siblings to cooperate and accept changes in their usual routine and caregivers. Some parents expected siblings to adjust to high change (being cared for by people outside the home) while other siblings had no change in caregiver and minimal change in routine. In other families, someone outside the immediate household moved in such as a grandmother. Parents reported that these substitute caregivers could maintain the siblings' usual schedules. Some parents made special effort to maintain face-to-face contact with the siblings while others did not.

When comparing the two groups, Knafl found no striking differences between the active and passive group in terms of type and length of hospitalization. Concerning the family structure, the active group had more families with children over 10 years of age (95.0% versus 5.0%) and the passive group had more families with preschool siblings (62.0% versus 30.0%). Generally sibling participation (active versus passive) is a function of age. When there are older siblings, parents view them as an asset and expect them to take more active roles.

On the follow-up interview done 4-6 weeks after discharge, parents reported siblings' reactions to the hospitalization. Thirteen of the 59 families reported negative sibling reactions, while only two parents reported severe responses. Parents in the 46 other families said siblings either responded positively by showing interest in the hospitalized child or they did not respond at all. The author contended that sibling participation varied in families but that most patterns of coping were quite successful. The children who did respond negatively tended to be in the high change families where the child was expected to adjust to both changes in routine and caregivers.

Characteristics Related to Specific Illness

Siblings of children with cancer.

Stresses on siblings of children with cancer have been reported with reactions including jealousy due to extra attention the sick child receives, fear of becoming ill, guilt in terms of causing the illness, along with feelings of grief and loss have been discussed by Binger (1973), Binger et al. (1969), Feinberg (1970), Heffron et al. (1973), and Kaplan et al. (1973). Iles (1979) described both positive and negative growth reactions of siblings with cancer.

According to clinical observations, siblings may experience stress of anxiety, depression, and isolation similar to the child patient (Groggin, Lansky, & Hassanein, 1976; Lansky & Gendel, 1978). Many of these difficulties come from adjustments the family must make once they find out a child has cancer.

Koocher and O'Malley (1981) interviewed 51 brothers and 50 sisters who had recovered from being cancer patients. Researchers used a semi-structured interview. Some of the reported findings were that siblings were disappointed they were not allowed to visit the patient in the hospital because of age restrictions. Sometimes the well siblings had problems with other children in school or had to defend the patient from ridicule by his/her peers. At least one-fourth said they felt jealous with another 19.0% admitting residual jealousy. About one-third of the siblings had worried they would get cancer too. Siblings, ages 6-10 years at the time of cancer treatment, may be most vulnerable to feelings of rivalry. Feelings of guilt seemed to be related to the lack of information about the illness. Closed communication systems in families may have contributed to emotional problems in siblings. Koocher and O'Malley also said that many problems could have been prevented if siblings had received direct factual information. Some siblings related positive aspects of the cancer situation by experiencing enhanced feelings of closeness and growth in their own coping skills. With time, sibling relationships seemed to be restored.

Working with a group of parents of children with acute leukemia, Heffron et al. (1973) found that siblings often become jealous of the hospitalized brother or sister due to the increased attention the patient received. When the patient's condition worsened, this jealousy caused the sibling to feel guilty. Thus, on the one hand siblings are fearful their brother or sister will die, but on the other hand, they are jealous of the attention given and the fact that the ill child gets to miss school.

While doing psychotherapeutic work with siblings of cancer patients, Sourkes (1980) noticed recurring themes of concern that siblings expressed such as: (a) cause of the illness; (b) visibility of the illness; (c) feelings of guilt and shame; (d) academic and social functioning; (e) relations with parents; (f) identification with the illness; (g) somatic reactions; and (h) sibling patient relationships. Sourkes also stressed the positive caring between siblings and patients and warned that to ignore this reciprocity of caring is to neglect the children's most adaptive means of coping.

Binger et al. (1969), in a retrospective study of 20 families which had lost a child from leukemia, found 50% of the siblings suffered emotional and behavioral problems. Parents cited a variety of problems siblings of the hospitalized child experienced. They had headaches, poor school performance, enuresis, school phobia, depression, severe separation anxieties, and persistent abdominal pains. Siblings often had feelings of guilt and concern that they, too, might suffer from the fatal illness. Parents' preoccupation with the sick child was interpreted as a rejection of the siblings themselves.

The 50.0% of siblings suffering emotional behavior problems that Binger et al. (1969) noted exceed the estimates in the general population which are approximately 10.0 to 20.0% according to the Joint Commission on the Mental Health of Children (1970). One wonders if an adequate comparison group was used and if the rates were inflated due to the subjective interview.

Cairns, Clark, Smith, and Lansky (1979) explored the impact of childhood cancer on siblings. This is one of very few studies where siblings themselves were interviewed. Siblings from 71 families were given one or more of the following tests: the Piers-Harris Children's Self Concept Scale; the Bene-Anthony Family Relations Test; and the Thematic Apperception Test (TAT). Of these 71 families, 11 had children who took all three tests, 40 had children who took two tests, and 20 had children who took only one test. The Piers-Harris scale was administered to 47 patients and 55 siblings. All results indicated normal self-concept for both groups. Among the 27 patient-sibling pairs on the Piers-Harris, there was no significant difference between the patients' and siblings' scores. The Family Relations test was administered to 36 patients and 31 siblings. The 14 patient-sibling pairs revealed significant differences between the siblings' and patients' test scores. Siblings viewed the mother as overprotective ($p<.05$) and overindulgent ($p<.02$). There was an interactive effect between status (sibling vs patient) and sex. Boys in the patient group and girls in the sibling group did not feel other family members had good feelings towards them. The TAT was given to 17 patients and 20 siblings. It was established that there were marked differences in TAT stories in length of responses and number of interventions between the patient and sibling groups. Siblings had higher scores in 12 of 14 content areas. This is not surprising because they talked longer. Conclusions drawn by Cairns and associates were that anxiety, fear for own health, social isolation, negative body image, and fear of confronting family members with negative feelings, along with other stressors, were found to be very similar for patients and siblings. Siblings, like patients, when confronted with a life-threatening disease, have to deal with a great deal of stress.

Spinetta (1981b) reported his findings on more than 100 siblings of cancerous children who formed part of a larger three year study. When each family entered the study, a psychometrist gave them a battery of tests to see each family member's level of functioning, the way in which the family met the day-to-day concerns of each of the family members, and the way in which the family met the medical needs of the ill child. After three years, the health care team completed the Family Adaptation Scale for each family in the study. Significant correlations were found between the health care team's response and the psychometrists' initial judgments. When comparing the findings from the extended health care team and the psychometrists' judgments, results indicated families could meet the medical needs of the patient and day-to-day needs of family rather well. However, the emotional needs of the family were more difficult to handle. The patients' needs were met the most, with mothers' and fathers' needs met nearly as well. Siblings' needs, however, were met significantly less adequately than other family members.

More specific highlights of the Spinetta (1981b) longitudinal study will be briefly described by age. Siblings, ages 4 to 6 years, had a significantly lower self-concept than patients of the same age group on the Brown IDS Self-Concept Reference Test. On the Family Relations Test, siblings scored more negatively toward self than patients did and more sensitively toward the patient than the patient did toward siblings. Siblings also viewed parents as more psychologically distant than patients did.

Scores of school age children, ages 6 to 12 years, showed significantly less adaptation during diagnosis, periods of remission, and when the disease was in long-term remission. However, patients' scores were the lowest at severe times such as during relapse or frequent clinic visits. In the Roberts Appreciation Test (a storytelling test), once again the sibling scores were more maladaptive in anxiety and depression.

Adolescents, ages 13 to 18 years, scored on the Family Environment Scale with significantly more conflict and lower in cohesion than did the patients. In the Roberts Apperception Test, conflict scores were higher for siblings than patients. Siblings' storytelling also contained more punishment and mutilation themes. However, patients scored at significantly higher negative levels in sentence completion tasks.

While siblings did not score at lower levels than patients on all items, they did score at significantly lower levels of overall adaptation. Siblings also had persistent levels of negative responses to the Kinetic Family Drawings. Drawings seem to indicate that at patient crisis times parents turn all attention to patient and s(he) is helped; however, siblings' drawings indicate they are left unsupported. Spinetta concluded that "siblings suffer at least as much and probably more than patients in unattended emotional responses to the disease and disease process" (p. 140).

Johnson et al. (1979) were concerned with the cycle of guilt and resentment the sibling goes through when the child with cancer receives special attention. Fear of catching the disease is common in siblings who have no information or open discussion about the disease.

In a retrospective study of five or more years after the diagnosis of cancer, Gogan, Koocher, Foster, and O'Malley (1977) interviewed 13 siblings, ages 8 to 28 years, and reported that there still were problems with the cancerous child and the well siblings. Problems in sibling rivalry were intensified; however, very few feelings of guilt and feelings of exclusion from a significant family crisis were described. Siblings tended to minimize the impact of the illness on them. They said no change occurred in themselves, but they sensed a change in the patient. Some siblings reported increased academic work and responsibilities.

Problems in sibling adjustment to a child with cancer may be manifested in acting out behavior at school or learning disturbances (Clapp, 1976). Bozeman et al. (1955) concurred that siblings of leukemic children may have school difficulties and illness.

Sibling characteristics during reentry have been studied by several researchers. Chodoff et al. (1964) studied families of fatally ill children and found that often the sick child returned home. Although eagerly anticipated, these visits were often very stressful due to behavioral problems of both the sick child and the neglected siblings but mostly due to interpersonal difficulties with relatives and friends. Hoffman and Futterman (1971) also worked with the reentry process in the home and showed the impact on siblings and other family members' mental health.

Kagen-Goodheart (1977) spoke of the child reentering the family unit. Siblings may be confused because they often think things will be back to normal. Also, siblings have difficulty managing the extra attention the sick child gets and may become jealous. The sick child is allowed to miss school. If parents focus primarily on the sick child, these behaviors can induce feelings of guilt, resentment, and jealousy in the siblings. If these feelings and behaviors are not managed, they can lead to personality problems.

Outpatient treatment means parents have to leave their healthy children and give attention to the sick child. This causes jealousy and resentment in siblings (Binger, 1973; Cairns, Clark, Smith, & Lansky, 1979; Clapp, 1976; Johnson et al., 1979; Kagen-Goodheart, 1977).

Siblings of children with other illness. Morse (1974) found in siblings of children needing renal dialysis and transplants that they, too, are concerned with all the attention parents give the sick child or fear they may also become sick.

Cleveland (1980), in her study of traumatic spinal cord injury, found that when the injured child returned home, an older sibling generally took the interpreter role between the injured and the family. Also, siblings and injured talked with each other, versus their parents, because they didn't want to upset their parents any more than they already were.

Vance et al. (1980) hypothesized that siblings and parents of nephrotic syndrome children will develop more psychosocial problems than healthy children. Seventy-nine siblings from 36 families were compared to 79 closely matched healthy children. Researchers went into the homes, conducted interviews, and used parent rating scales. Children completed Self Observation Scales, and teachers gave estimates of the child's achievement, ability, and behavior along with information about absenteeism. In general, the frequency of serious problems between the two groups was less than anticipated. The findings, however, did suggest increased vulnerability among parents and siblings of children with nephrosis. The T-scores of siblings, while not being greatly disturbed, were closer to being abnormal than those of the control children. Parents often denied the stress, while siblings showed decrease in social confidence, less self-acceptance, inhibition, poorer academic performance, and less aggression. Vance et al. (1980) urged those who work with families of chronic illness to stay alert to similar problems.

In a study of 25 mothers of hospitalized children where 20 had other children in the home, Freiberg (1972) found that mothers also said the siblings were upset in some way. Six mothers explained that the siblings missed the hospitalized child; five others reported the siblings were frightened and anxious; the others said their siblings were upset because they missed their mother and did not want to stay with a babysitter or relative. When interviewed, the mothers frequently said things were not back to normal with their family.

In one controlled study, Lavigne and Ryan (1979) assessed the psychologic adjustment of 3- to 13-year-old siblings of pediatric hemotology (N = 62), plastic surgery patients (N = 37), cardiology (N = 57), and healthy siblings (N = 46). Siblings chosen for study were the oldest and youngest within the age range specified. The assessment measure was the Louisville Behavior Checklist in which parents described their children. The researchers concluded that siblings of chronically ill children are at a high risk for behavior and adjustment problems. The patient groups were more likely to show symptoms of social withdrawal and irritability. Various illnesses seemed to differ in the negative effect on well siblings. In children, ages 3 to 6 years, significant differences were found with siblings of patients undergoing plastic surgery (visible illness). These children showed the most psychopathology. In children, ages 7 to 13 years, there were more emotional disturbances in male siblings of patients with blood diseases than in the female siblings.

Sigal, Chagoya, Villeneuve, and Mayerovitch (1973), in a retrospective study, investigated 12 families in which one child before reaching 5 years of age had been hospitalized for severe croup. These children were then compared to their healthy siblings. Parents rated the behavior of the previously ill child and one of his/her siblings using the Quay and Peterson's Behavior Problem Checklist and the Sigal-Chagoya Child Behavior Inventory. Each child, in turn, rated the parents' attitude toward him/her using the Schaeffer's Child Report of Parental Behavior Inventory.

Significant differences were found in the children's perceptions of their parents and their parents' behavior toward them. The previously ill children saw the following attitudes significantly more often than their siblings: mothers showed more positive involvement with them, exerted psychological control, were intrusive, did not enforce rules, set high standards, and did not foster independence; and fathers were viewed as exerting hostile control and being intrusive. Parents perceived the previously ill child as having significantly more conduct problems, excessive dependence, and testing of limits. Parents perceived the sibling as curbing his/her aggression significantly more than the previously ill child. The authors feel their study confirms that early childhood illness may result in later parent-child relationship disturbances.

Two studies which used control groups and objective personality measures to study the adjustment problems in siblings of physically ill or handicapped children were done by Gath (1972) and Tew and Laurence (1973). The Tew and Laurence study used the Bristol Social Adjustment Guide and found siblings of patients with spina bifida were more than four times likelier to show signs of maladjustment than healthy control children. There also was a nonlinear relationship between the severity of the illness and sibling adjustment to it.

In another study utilizing controls, Gath (1972) used standardized problem checklists to compare 36 school age siblings of 22 children with Down's Syndrome and 35 school age siblings of 21 children with surgically repaired cleft lip/palate deformities. Children were 8½ to 12 years old. Results indicated no elevated rates in adjustment problems. The discrepancy in the Tew and Laurence (1973) study may suggest that the effects of each illness may be specific to the disease. Thus, effects on sibling adjustment may vary from illness to illness.

Gath (1972), Knafl (1982), Lavigne and Ryan (1979), Tew and Laurence (1973), and Vance et al. (1980) believed the findings of these studies are inconclusive. Because of the variety of instruments used and groups compared, it is difficult to draw any definitive conclusions from these studies.

<u>Siblings of children with terminal cases and death</u>. Literature on parental bereavement has been growing (Hilgard, Newman, & Fish, 1960), but Feinberg (1970) maintained that little has been written on sibling reactions to the death of a brother or sister. Data defining the difficulties siblings and parents experience after the death of a child (Lascari & Stehbens, 1973) are almost nonexistent. Feinberg (1970) also stated that only a small amount of preventative therapeutic work has been done with this population. Feinberg presented a clinical study in which brief therapy was used with two sisters adapting to their brother's dying.

Jealousy, anger, and resentment toward the parents were exhibited by the children. The two children even wished they had gotten sick at times. It was Feinberg's belief that brief therapy helped the siblings ventilate their feelings at a time of great stress and prevented later behavioral or neurotic complications.

In a follow-up interview study of 20 families who had experienced a child dying from leukemia, Lascari and Stehbens (1973) and Stehbens and Lascari (1974) found that there were few adverse reactions in the 64 surviving children after the death of a brother or sister. The majority of siblings (70.0%) were considered back to normal in a week. There were 12 cases reported where dysphoria, enuresis, abdominal pains, and restless sleep were noted. Seven siblings had a decline in school performance, but this lasted only a few months. A minority of the parents decided to tell the siblings of the terminal probability of the disease, believing siblings would not understand. Otherwise parents reported answering sibling questions about the nature of the illness factually. Ninety percent of all the children attended the funeral; those who did not were all under 5 years of age.

Heffron et al. (1973) mentioned that it is easier for siblings to handle the reality of death of the leukemic brother or sister if it comes from parents rather than peers or a TV show. Parents believed it was best to mention the possibility of death early in the treatment of disease.

Little (1977) found that parents tend to inform older healthy siblings of a terminal diagnosis but may withhold it from the younger healthy siblings. Many of the older siblings seemed to be able to handle the situation and help the parents. However, some older siblings and many preschool children were not able to cope with a terminal diagnosis and evidenced depression, enuresis, and school problems.

Lindsay and MacCarthy (1974) reported developmental observations of siblings of a dying child. They suggested that the infant sibling is at the most risk because the parents are too preoccupied with the sick child. The toddler senses the change in the family and interprets it as parental rejection. The school age sibling also senses the family anxiety and feels anger and resentment. The role of caretaker is often taken on by older siblings who use this role as a defense against how they really feel. Similar conclusions have been drawn by Hendin (1973), Share (1972), and Wiener (1970).

The fact that when a child dies, siblings, along with fathers and grandparents, are the forgotten grievers was suggested by Gyulay (1975). Siblings' questions are not answered because family life is disrupted at the time of death. Siblings may have felt angry or jealous at the attention, presents, and mail the sick child received. Thus, grades may even decline along with a diminishing attention span. The sibling may feel rejected by adults, and this isolation feeling may turn into panic and self-hate. Some siblings develop the same symptoms the ill child has and even have side effects similar to those the ill child has from chemotherapy treatments. On the other hand, some siblings try to spare the parents additional worry and do not tell them physical or emotional problems. Gyulay even went on to say most parents seem to resent their healthy siblings' complaints. Blinder (1972) found siblings had somatic complaints similar to the dead child.

Timidity and social withdrawal were found in siblings of children who were dying or had died (Blinder, 1972; Wold & Townes, 1969). Wold and Townes also reported girls to be more withdrawn and boys to exhibit more aggressive behaviors.

Binger et al. (1969) said siblings manifested their reaction to death of a brother or sister in varying ways. Some children worked out their grief through play while others cried and verbalized their grief directly. Some children seemed nonchalant at the time of death but overreacted to the loss months later. Still others did not grieve openly but exhibited behavioral changes. Binger also noted that many of the siblings felt responsible for the death and thought they, too, would die of the disease.

Siblings of children with handicaps and/or mental retardation. Gath (1972) investigated a group of 36 school age siblings of children with Down's Syndrome and another group of 35 school age siblings of children with cleft lip/palate. These children were compared to 71 individually matched school children. Behavioral questionnaires (Rutter Scales A_2 and B_2) were completed by parents and teachers for all siblings and controls. No significant difference in the behavioral rating was found for the siblings of Down's Syndrome and cleft lip/palate and the control children. This did not reaffirm earlier findings by Holt (1957) and Schonnell and Watt (1957) that sibling mental health was affected.

Another study by Gath (1974) compared 85 brothers and 89 sisters of 104 Down's Syndrome children. Parents and teachers completed rating scales. A disturbance in girls rather than boys was found. Disturbance in girls in relation to the Down's Syndrome child could be related to birth order, type of school, and age. It was concluded that elder sisters who probably carry a large burden of the care are most affected.

Poznanski (1969) wrote about the psychiatric difficulties siblings of a physically or mentally handicapped child may face. Often families give extra time and attention to the handicapped sibling. The effect of this emphasis upon the brothers or sisters does not seem important at the time. Child psychiatrists, however, see more siblings of handicapped children than the handicapped children themselves. The relationship with the well siblings and mother can become distorted because the extra attention given to the handicapped sibling is interpreted by normal siblings as meaning they are not as loved. Therefore, parents must take care in the emotional growth and development of the other children in the household.

Having a retarded sibling in the home may affect life goals of children (Farber, 1963). Eighty-three boys and girls, ages 10-16 years, ranked a series of life goals. Mothers provided data about the frequency of interaction between the normal sibling and the retarded child. Both boys and girls who interacted daily with their retarded siblings were not as concerned about goals of success in personal relations such as having close friends, focusing life around marriage and the family, or on being a respected community leader. Also, the boys and girls who had sustained interaction with the retarded siblings chose devotion to a worthwhile cause and making a contribution to mankind to be important.

Cleveland and Miller (1977) tried to find out if the life commitments of normal adult siblings had been influenced in any way by having a mentally retarded sibling. Ninety men and women who were siblings of mentally retarded adults participated in answering questionnaires. In most cases, the life commitments of the normal siblings were not affected by having a mentally retarded sibling. Cleveland and Miller also concluded that most families were flexible and could cope with difficulties of having a retarded child in the home. Most also provided an adequate environment so the other children could develop normally. However, the only female sibling or the oldest daughter seems to present a conflict in role demands. On the one hand, parents push these children to fulfill their various wishes, while on the other hand, they attach parent surrogate responsibilities to them. These female siblings reported much more frequently that they did not get enough attention from their parents, and this, in turn, influenced their family decisions and careers.

"The presence in the home of a child handicapped from birth clearly presents problems to the family but it is less clear that the mental health of the family is affected" (Gath, 1974, p. 188).

Jordan (1962), studying the mentally retarded, suggested that younger siblings may be more at risk than older siblings. This is due to the fact that the younger sibling who generally plays a more dependent role may be uprooted when a sick child assumes the more dependent role.

Sex differences may also make a difference. Farber (1959) noted that normal sisters of the mentally retarded had more personality problems when the retarded child lived at home, and brothers seemed to have more behavior problems when the retarded child was hospitalized.

Often studies report the negative impact of an illness or handicap on the well sibling; however, Caldwell and Guze (1960) showed that siblings of mentally retarded children tend to be more understanding of children with special problems.

Siblings of children with cystic fibrosis. Gayton et al. (1977), using interview and formal psychological measures, found that 31 siblings of children with cystic fibrosis, ages 5 to 18 years, had little negative psychological impact. In fact, the total self-concept score on the Piers-Harris Self Concept Scale for the siblings was higher than data reported for normal children by Piers (1972). Gayton et al. (1977) explained these differences by suggesting that speculations regarding the negative impact on siblings are anecdotal in nature and may have arisen from biases.

Burton (1975), however, found about one-third of the sample studied had problems with sibling behavior due to having a sick child in the family. Burton (1975) and Gayton et al. (1977) lack comparative data from families without ill children. Consequently, drawing conclusions is difficult.

Turk (1964) felt there are major problems in communication in families with children who have cystic fibrosis. Tropauer et al. (1970) referred to negative impact on siblings concerning school adjustment difficulties, learning problems, and delinquency.

Pless and Pinkerton (1975) determined that handicapping illnesses do not invariably result in maladjustment but instead may provide opportunities for personality growth. Gayton et al. (1977) suggested that "focusing on strength and resilience of children with cystic fibrosis and their families would contribute to an increase in knowledge regarding coping strategies and perhaps provide us alternative ways of helping such families" (p. 894). Again the above studies lack comparative data, so it is difficult to draw firm conclusions.

Speaking from experience, Grossman (1975) was convinced that siblings of cystic fibrosis patients may be ashamed of the child's illness or even resent the demands made upon the family. However, siblings may also worry about losing their brother or sister and may also try to help him/her.

According to Harder and Bowditch (1982):

> Researchers have not questioned the siblings themselves concerning their perceptions of the impact of the disease on them and their families. Because one's perceptions constitute one's reality, it seems important to examine how these children believe their disease has affected them (p. 117).

At this point, Harder and Bowditch began their study. Fourteen families and 19 subjects agreed to participate. Siblings were 7 to 16 years old. A structured interview was set up regarding the impact of cystic fibrosis on the family. The consensus was that cystic fibrosis affected their family life in that it had a positive force on the family. Besides reports of drawing the family closer together, some siblings felt they were less self-centered since their brother or sister had cystic fibrosis. The two problems mentioned most frequently were increased financial strain and increased chores. Less frequently mentioned problems were that parents had initially spent too much time with the ill child and that the ill child would misbehave. Four of the 19 subjects still felt the ill child received too much attention from the parents. Sixty-three percent said they did not worry about getting cystic fibrosis, and 8 of 19 felt they should have gotten the cystic fibrosis instead of the siblings, but the authors believed that only one felt guilty.

Harder and Bowditch (1982) continued by stating that another 63.0% stated they were not embarrassed. While 46.0% said they felt no anxiety and 32.0% felt little anxiety, 11.0% reported some and 11.0% a lot. As far as worrying about the diseased sibling dying, 32.0% did not, 32.0% did a little, 20.0% did some, and 16.0% did a lot. Forty-three percent of the siblings did not worry about others in the family dying, but 47.0% worried a little. The authors concluded that there was a lack of support for the assumption that chronic disease always has a negative effect on family life. Sometimes living with a ill sibling is a positive growth experience. However, the authors believe "we must remain sensitive to the potential for negative consequences of any long term stress" (p. 120).

Siblings of children with schizophrenia. Studies have also been done to explore what impact, if any, there is on a sibling having a schizophrenic for a brother or sister. Samuels and Chase (1979) interviewed 14 siblings ages 24-46 years old. As a group, the subjects functioned at a high level of adjustment. Older subjects tended to become reinvolved with the ill sibling, and some began assuming responsibility for him or her. Guilt was a predominant emotion, and intensity of guilt seemed to vary with ordinal position. Some of the older siblings expressed guilt over earlier sibling rivalry while younger siblings felt guilt over being well.

Summers and Walsh (1980) compared parental relationships of schizophrenics and their well siblings by projective tests and questionnaires. Schizophrenics differed from their well siblings by tending to see themselves as symbiotically attached to their mothers and failing to be accommodated by their fathers. Schizophrenics also seemed to align themselves with the same sex parent.

Samuels and Chase (1979) mentioned that there is very little information to be found about siblings compared to the extensive literature on parents and children of schizophrenics.

In summary, there is not a great wealth of studies on well siblings per se. Data gathered had to be gleaned from research where well siblings were not the dominant topic. Reactions of the siblings of hospitalized and ill children varied. Some well siblings are affected positively and some negatively. Considering that most of the studies are parent reported and are very subjective in nature, no definite conclusions can be drawn.

Families of Hospitalized and Ill Children

Hospitalization and illness of a child influence family life as a whole no matter what the response or acceptance is. General characteristics, disruption of family life, and finances are herein discussed.

General Characteristics

Much has been written concerning the effects of illness and hospitalization upon the child (Issner, 1972). Koocher and O'Malley (1981) said, "For the most part, research studies have focused on parents, rather than on the family as a whole and concentrated on mothers rather than fathers" (p. 13). Issner (1972) urged that when dealing with the hospitalized child we must be aware that s(he) is part of a total unit, the family. Clark (1979) also contended that when hospitalizing a child, the hospital staff is not just dealing with the patient but an entire family. Teyber and Littlehales (1981) maintained that it is not possible to discuss the emotional reactions of a hospitalized child outside the family context.

"Serious and prolonged illness such as childhood leukemia is a common source of stress that poses major problems of adjustment, not only for the patient but also for family members" (Kaplan et al., 1973, p. 60). These same researchers noted that "when individuals belong to families, they do not resolve their own problems of stress independently, nor are they immune to effects of stress that may be concentrated in another member of the family" (Kaplan et al., 1973, p. 60). A seriously ill child places tremendous stress on family functioning (Battle, 1975; Prugh et al., 1953). The family, however, is a uniquely organized group to carry out stress mediating functions and is in a strategic position to do so (Vincent, 1967).

Mechanic (1964) concluded that the family as a whole should be studied in relation to the sick child.

> There is no more devastating experience in the life of a family than the fatal illness of a child. It tears into the family's life as a functioning unit and confronts each family member with the crisis in coping with loss and grief. The shock extends from parents and siblings to involve grandparents, other family members and friends" (Schoenberg, Carr, Peretz, & Kutscher, 1970, p. 87).

Issner (1972) summarized that illness has an impact upon the whole family unit as well as on the patient.

Battle (1975) dramatized:

> Being chronically ill is vastly different from being acutely ill. It stresses and drains the child and every family member over an indefinite period of time. The wonderful resiliency of the human being is stretched almost beyond endurance especially if there is no prospect of improvement, and even more, if the child deteriorates with the passage of time (p. 525).

Similarly, many factors determined the impact of the handicap or chronic illness on the child. The factors were: type of handicap; how much the family accepts and responds; intellectual capacity of the child; if it concerns a congenital or acquired condition; the kind of medical and surgical procedures; and how often they are needed; and the way the mother handles the reality of the child's condition (Howell, 1973; Mattson, 1972).

Hodapp (1982) stressed exploring the child's needs farther than just the interaction with the mother. The patient's experience with cancer cannot be understood without looking at his/her role in the family. Neither can the child learn to cope with the illness and its stresses without considering the rest of the family in the intervention strategy.

Disruption of Family Life

Even though families showed resiliency in the face of hospitalization of one of the members, family life was disrupted (Litman, 1971). While almost one-third of Litman's sample reported no major problems for the family, most felt it did disrupt the family. They cited missing the patient, disruption of home activities, inconvenience, and restricted mobility. Salk, Hilgartner, and Granich (1972) studied families who had a child with hemophilia. Forty-three percent of the families felt they were socially restricted, and over three-fourths reported an adverse effect on family mobility such as being able to change jobs or residence or to travel.

According to Litman (1971), the extent to which a family member's illness may affect his/her role relations seems to be a function of the illness itself. The longer and more complicated the illness, the greater is the chance of it affecting the member's role relations. Sixty-one percent of the families said the patient's illness did not tend to create great difficulty for the family members. When it did, the major problems mentioned were inconvenience and restricted mobility of the family because of the patient's illness.

Koocher and O'Malley (1981) spoke about shifts in roles and household tasks and responsibilities of family members when a child is ill. Gathering data from parent interviews, Knafl (1982) reported that parents require the older well siblings at home to take on more responsibilities when a child is hospitalized. Johnson et al. (1979) suggested that centralizing cancer care has brought about problems for the family. These include traveling long distances to treatment centers and finding accommodations, transportation, and babysitters. Morse (1974), too, discovered that the difficulty of transportation to the hospital for pediatric dialysis disrupted family life.

In another study, a researcher interviewed 25 mothers and discussed the effects of hospitalization on their child, ages 15 months to 9 years, and the family (Freiberg, 1972). Mothers reported that family life was considerably disrupted. The 20 mothers who had other children needed to make arrangements for hiring babysitters, sending their children to stay with a relative, or arranging to have the father spend extra time at home. Siblings were reported to be upset. Even after the ill children had returned home, the households were not back to normal.

Cleveland (1980) studied 19 families where a son or daughter had a traumatic spinal cord injury. Fathers, mothers, the injured child, and siblings completed lengthy questionnaires. Data were gathered in two phases, one at the beginning of rehabilitation and again six months after the injured child's release from the rehabilitation institution. The researcher discussed the result the illness had on family structure in terms of task organization, affection structure, communication structure, power structure, and family unity. Concerning task organization, 14 families reallocated household tasks, and five brought in an outside relative. Fathers and siblings reported a lack of role strain while mothers and the injured son or daughter felt increasing role strain. The affection structure of the family was also studied. Immediately following the injury, there was an upsurge in feelings of intra-family closeness. Gradually, the affection structure changed and became more complex and discriminate in terms of developing specific "close" dyadic relationships.

The family communication structure in Cleveland's study became centered around the injured after the stressing event. Both noninjured and injured siblings reported more post-injury openness. As noted previously in this review of literature, the siblings discussed the crisis with each other rather than mother and father because they did not want to upset them.

Concerning the family power structure of phase 1, all said the parents were most powerful. However, by phase 2, the injured child and the father were reported as having the most power. Finally, Cleveland investigated family unity. During phase 1, family members all felt they could deal with the crisis. By phase 2, the family experienced lower levels of family unity since the realities of dealing with the physically disabled sibling had set in. Sharp decreases in the "closeness" of the family as a whole also resulted.

Litman (1971) found most of the families (75.5%) in his study said the illness of a family member had little effect on family solidarity. An equal number of subjects, however, said the illness either made the family relationship more difficult or drew the family closer. There was little, if any, evidence that marital happiness, or strong family solidarity, or family ties provided any hedge against the disruption in family relations caused by a member's illness. When Morse (1974) studied families involved in pediatric dialysis, he found that families with close ties were brought closer together and that divided families were torn farther apart by medical crises.

A number of investigators noted that, after the initial shock, families must face a number of new complex emotional and practical problems as a result of the long periods of treatment and long-term uncertainty about the future which accompany improved prognosis for childhood cancer (Clapp, 1976; Johnson et al., 1979; Kagen-Goodheart, 1977).

Kagen-Goodheart (1977) enumerated several stresses in terms of what is involved for a family when their child becomes an outpatient. Transportation may leave parents tired. Finding someone to care for the sick child while parents work is hard. It seems that if fathers are able to participate in the treatment process, families have fewer conflicts around meeting the physical needs of the ill child at home. However, if only the father works outside the home, the burden of all outpatient treatment falls on the mother which may result in the father feeling guilty for his lack of involvement.

Another aspect of stress for families of children with cancer is the treatments the child must have. The need to sign consent forms may be frightening in light of the statement about the side effects (Johnson et al., 1979). Johnson et al. (1979) and Kagen-Goodheart (1977) also noted that "coming off treatment" can be another stressful time for families because it is hard for families to believe their ill child can be all right without treatment. Kagen-Goodheart (1977) went on to explain that parents fear relapse and face difficulty in treating their child as they did prior to the illness.

Finances

Koocher and O'Malley (1981) noticed that much investigative research of the effects of childhood cancer on the family is based upon the now out-of-date assumption that childhood cancer is an inevitably fatal disease. Advances in medical science in treating cancer patients may add new types of stress on the family. For instance, outpatient cancer treatment for a child may be physically exhausting to the family. Often, the treatment center is not in the family hometown so travel and overnight accommodation expenses are incurred (Koocher & O'Malley, 1981). These types of expenses can become financial burdens (Johnson et al., 1979; Kagen-Goodheart, 1977).

In an early study done by Bozeman et al. (1955), mothers reported anxiety about finances and transportation. Lansky, in a series of studies

(Lansky, 1974; Lansky & Gendel, 1978; Lansky et al., 1978; Lansky, Lowman, Gyulay, & Briscoe, 1976), looked at the stress childhood cancer imposed on family members. The financial burden of their child's illness was found to be a very great source of distress. In fact, it rated second to the child having cancer. Most families had some type of third-party coverage for medical expenses. However, the nonmedical expenses were particularly worrisome. Rice (1967) reported that both direct (medical) and indirect (nonmedical) costs of cancer in adults were staggering.

The above reports led to a study by Cairns, Clark, Black, and Lansky (1979) of the nonmedical costs of childhood cancer. Seventy families of children who had cancer were asked to fill out questionnaires and keep logs on their daily expenses. The nonmedical costs varied with the median total weekly expenses being \$39.70, the mean was \$56.40, and the standard deviation was \$54.18 with a range from 0 to \$266.70 per week. The largest expense categories were transportation, food, and miscellaneous expenses. The four variables which explained approximately 47.0% of the variability in total expenses were: level of care (meaning was the patient having a great deal of care or little care); performance status; family size; and distance from the hospital. The most important variable for predicting each category of expenses except lodging was level of care. As one might assume, families whose children were hospitalized the entire week had the highest nonmedical expenses followed by those whose children spent part of the week in the hospital. Families of outpatients and children who had little or no contact with the hospital had fewer expenses during the week. Therefore, the authors concluded that out-of-pocket nonmedical expenses are sizable for families of children with pediatric cancer.

In summary, family life is affected when there is a hospitalized or sick child. Various factors influence the kind and amount of disruption. While some sources seem to point to a large disruption of family life, others mention the resiliency of the family as a unit. Studies indicate that finances, both medical and nonmedical, especially in long-term illness are a real concern to the family.

Ameliorative Efforts

Hodapp (1982) wrote that "countering risk factors is the notion of 'ameliorative possibilities' or types of environments and procedures which limit some of the effects of hospitalization" (p. 85).

Since hospitalized and ill children produce a great deal of trauma in the lives of families, ameliorative efforts on their behalf are necessarily many. This section concerns emotional and informational needs of parents, sick children, and siblings as they make adjustment to the illness as well as problems encountered in the hospital environment.

Parents

Parent needs. Parents feel various needs when they have a hospitalized or ill child. When the needs of parents are not met, there are usually emotional repercussions for both parents and the ill child. Such emotional reactions will occur even when the hospital does its best to meet all of the parents' needs because hospitalization of a child is an emotional trauma in and of itself (Mason, 1978).

Smitherman (1979) stated that all too often the nursing staff has viewed parents as a hindrance and an annoyance. The author concluded:

> (1) parents need to see that their child is receiving competent physical care; (2) parents need to understand the medical condition and treatment of their child; (3) parents need to feel important to their child and capable as parents; (4) parents need a chance to discuss their feelings about their child's hospitalization; (5) parents need to learn more about being honest with their children (pp. 1423-1424).

Bozeman et al. (1955) found that 20 mothers of leukemic children requested three needs most frequently during the illness of their child. These needs were: tangible services such as transportation and housekeeping; a temporary escape; and emotional support. Droske (1978) pointed out the need of parents to be informed of posthospital changes their child might experience. It is also important to express confidence in parents' ability to cope (Love, 1970; Haller, 1967).

The following will be a review of parents' needs for information and communication. Clapp (1976), Friedman et al. (1963), and Johnson et al. (1979) stressed that parents of children with an illness such as cancer need continued education about the illness on a level they can comprehend so they can grasp realistically the condition of their child. Parents of 20 deceased leukemic children who were interviewed by Lascari and Stehbens (1973) also mentioned they wanted facts and appreciated the physician's honesty. On the other hand, Murstein (1960), in an older study, found that extensive communication from the physician to the parent had a negative impact on the emotional adjustment of parents of leukemic children and a more positive effect for parents of nonleukemic children. Ten parents of leukemic children and 10 parents of nonleukemic children participated in the study.

Clark (1979) pointed out that all parents of children who are hospitalized need information. They need specifics as to what is wrong with their child and continual progress reports. Parents also need information as to the hospital's staff, policies, and admissions, along with support and reassurance that someone will be willing to help them. According to Mumford and Skipper (1967) and Skipper (1965), the lack of information a patient receives, along with a lack of emotional warmth from medical staff, are some of the most criticized aspects of hospital care. Hardgrove and Kermoian (1978) discovered children of parents who are kept well-informed of the illness and receive guidance about the parental role recover more quickly than children of parents who are less well-informed.

In Koocher and O'Malley's (1981) study, after interviewing 190 parents representing 199 children who had survived cancer, the parents recommended that caregivers should provide factual and direct communication about their child's cancer and his/her condition. Special information on financial resources was requested, as well as assessment of the family emotional support system. Still another recommendation was that the physician should first tell the parents the diagnosis, and then both the parents and physician should tell the child.

These same parents made several recommendations for other parents who find they have a child with cancer. A few of their recommendations included encouraging the parent to ask questions and to not feel foolish about doing so. Also, parents recommended that parents tell the child about the diagnosis immediately. They also advocated not overindulging or overprotecting the sick child and actively seeking out someone who would listen to their feelings (Koocher & O'Malley, 1981).

The importance of a family conference by the physician with the entire family of the leukemic child was stressed by Ablin, Binger, Stein, Kushner, Zoger, and Mikkelson (1971) and Binger et al. (1969). This discussion not only gives the family much wanted information, but it also seems to build trust between the family and the physician.

Kaplan et al. (1973) warned against dishonest communication about the illness which only creates distrust in the family. They also recommended that both parents need to tell the family the nature of the illness even if it results in grieving by family members. Johnson et al. (1979) recommended that physicians also tell the child patient. In the past, when parents and physicians have avoided telling the older child about the diagnosis, they found the child had already discovered it. Stehbens and Lascari (1974) reaffirmed the need for honesty and good communication between the medical staff and the parents. Poor communications, or even a failure to communicate, can make adjustments to the illness by the family exceedingly difficult and may even place greater strains on the marriage (Binger et al., 1969; Kaplan et al., 1973; Pearse, 1977). Stehbens and Lascari (1974) found parents wanted honest and frank discussions of the realities of the disease.

Parent Preparation and Intervention. Studies by Irwin and Lloyd-Still (1974) and Robinson (1972) have shown parental anxiety over a child's hospitalization is due to preparation of their child for surgery, giving up their child's care to others, the surgery outcome, guilt feelings about disciplining the sick child, and coping with the child after hospitalization.

Mahaffy (1965) and Skipper, Leonard, and Rhymes (1968), in a series of clinical nursing experiments, concentrated on providing supportive and preparatory efforts for mothers rather than ill children. The rationale for these studies comes from the social interaction theory and the emotional contagion hypothesis (Campbell, 1957; VanderVeer, 1949). The hypothesis states that a parent's emotional state may be transmitted to his/her young child. The results indicated mothers who received the experimental treatment showed less distress and were more satisfied with information and medical care the child received. In turn, the experimental group of children also showed less emotional distress.

In a study of 46 mothers who had children in the hospital for tonsillectomies, Skipper (1966) found that a child's hospitalization for surgery is distressing for both mother and child. He also found that mothers who received advance information from the physician made a more rational adaptation to their child's hospitalization and also had less distress than mothers who did not receive adequate information. Studies with hospitalized adults (Andrew, 1970; Healy, 1968; Vernon & Bigelow, 1974) endorsed the fact that accurate information has positive effects on the way an adult deals with stress. Johnson (1972), in a study related to the above findings, concluded that the intensity of anxiety a person believes is involved in a pain experience is really a function of the degree of incongruity between the actual physical sensation experienced and the sensations the person expected.

An extension of Skipper's (1966) study was done by Skipper and Leonard (1968). This time the researchers hypothesized that hospitalized children's stress can be reduced indirectly by reducing the stress of the mothers. Eighty mothers with children, ages 3 to 9 years, who were admitted to the hospital for tonsillectomies were examined during admission. The experimental group mothers received the attention of a special nurse who tried to create a relaxed atmosphere, provided accurate information, and encouraged verbalization of feelings. The nurse also made brief contacts with the mothers during distressing times. The control group mothers had routine hospital care. The experimental mothers reported less distress than the control mothers, and this, in turn, seemed to affect the ill children. The children of the experimental mothers showed more favorable physiological indicators such as lower systolic blood pressure, lower pulse rate at discharge, and less postoperative emesis.

Still another study that focused on preparation on children's and parents' stress responses was conducted by Visintainer and Wolfer (1975). Eighty-four children, between the ages of 3 and 12 years, who were hospitalized for elective surgery and their parents were assigned to one of the following four groups: stress point preparation; consistent supportive care; single-session preparation; and the control condition. Conclusions drawn were that children and parents who participated in the stress point preparation were significantly less upset and more cooperative than children in the other treatment groups. These results along with the findings of Ferguson (1979), Mahaffy (1965), Skipper and Leonard (1968), Skipper et al., (1968), and Wolfer and Visintainer (1975) support the hypothesis that systematic preparation and support increase the child's cooperation and decrease behavior problems in posthospital adjustment. Thus, parents reported less anxiety and more satisfaction with the amount of information received and care given.

Studying children with burns, Woodward and Jackson (1961) found a high amount of disturbance. Indicators of distress or disturbance were sleeping and eating problems, enuresis and soiling, fears, temper tantrums, apathy, and withdrawal. Half the mothers of this group of children received emotional support and information from the hospital staff who also did follow up work on the children for a year after hospitalization. After a year, emotional distress in their children was noted by 20.0% of the mothers in the supported group and in over 80.0% of the nonsupported group.

Wolfer and Visintainer (1975) divided children, 3 to 12 years of age, who were going to be hospitalized for tonsillectomies into five groups. These were as follows: home-booklet preparation; stress point preparation; home preparation plus stress point preparation; home preparation plus consistent supportive care; and a control condition. Results indicated children who received home preparation materials only, or in a combination with other treatment conditions, exhibited better adjustment than children in the control treatment. It was also found that inhospital preparation was as effective as in home preparation or any combination of in home preparation.

Shifts in authority and caretaking. Chodoff et al. (1964) talked about the fact that once the child is hospitalized and begins treatment, parents soon see the shift in authority from themselves to the medical staff as the primary caretakers of their child. This is often seen as a threat to the parent's self-esteem. Bozeman et al. (1955) also reported mothers' distress over being deprived of important maternal functions. Parents often feel powerless to help their child in the hospital and feel their "mothering" role has been usurped by the nurses (Smitherman, 1979). Hardgrove and Rutledge (1975) contended that "parents are the major support system of the young child" (p. 836). Instead of taking the primary caretaking responsibilities away from the parents, Hardgrove and Rutledge (1975) described a program at the Moffit Hospital in San Francisco where parents helped monitor IVs and are encouraged to stay with their child, measure calories, weigh diapers, and feed their child along with other tasks. In other studies, mothers found the nursing role consistent with their past caregiving experiences and wanted to participate in the hospital care of their child which helped allay feelings of guilt (Friedman et al., 1963; Knudson & Natterson, 1960; Orbach et al., 1955). If the medical staff views parents as an integral part of the treatment team, parents feel more useful. Thus, parents' roles could switch from the nonparticipant observer to a principal caretaker who could tell the nurse about the child (Freiberg, 1972).

Parent groups. Medical technology has made progress in the treatment of the seriously ill patient; however, the technology has led to increased depersonalization and mechanization (Irwin & Lloyd-Still, 1974). Orbach et al. (1955), in an early study, suggested that helping a family cope with a child diagnosed with a serious disease often requires the service of a team comprised of diverse disciplines. Evans and Edin (1968) suggested a multidisciplinary approach. One way to incorporate a team approach and to help parents cope with modern technology and their anxiety is through parent groups or parent meetings.

Levine and Schild (1969) said that by giving the parents in a group an opportunity to help others facing a similar problem, the parents' own individual adjustments would be facilitated. Kartha and Ertel (1976) tried to relieve parental anxiety by forming a group treatment program led by a social worker. The social worker met seven times with six mothers of children who had leukemia, each session lasting 90 minutes. Topics discussed were: impact of terminal illness on the family; effect on the well siblings; ways to provide emotional support; problems in family discipline; the meaning of hospitalization; side effects of treatment; the patient's relationships to friends and school; and terminal care. All the mothers felt the group was helpful. Similarly organized support groups for parents of children with cancer were mentioned by Binger et al. (1969), Bozeman et al. (1955), and Friedman et al. (1963).

Weekly meetings led by two social workers proved effective in helping parents minimize the emotional reactions to hospitalization and surgery of their children. The sessions also increased the hospital's responsiveness to the needs of both parents and children (Irwin & Lloyd-Still, 1974). Clark (1979) reported parents who had children in a pediatric unit at Sinai Hospital in Baltimore found the bi-monthly parent meeting helpful. Major themes in their group meetings were: communicating problems with the hospital staff; parents' feelings of guilt or anger over their child's illness; the decision to stay overnight; and concerns regarding management and limit setting of children in the hospital. As did Clark (1979), Irwin and Lloyd-Still (1974) noted that parents found the meetings helpful and appreciated being helped to cope with anger and complaints.

Still another important function of parent group meetings is to help teach parents to talk out some of their problems and help establish more open communication within their families (Heffron et al., 1973; Kartha & Ertel, 1976; Knapp & Hansen, 1973). Bozeman et al. (1955) found that parents of children hospitalized with leukemia would seek each other out in the lounge, thus forming spontaneous groups which functioned as an important source of emotional support. However, it must be noted that Binger et al. (1969) advised that informal groups formed by parents themselves without professional leadership may lead to inappropriate sharing of sorrows and may increase the emotional burdens of parents.

Hospitalized and Ill Children

Factors which aid adaptation to the hospital. A lengthy list of suggestions that would help the hospitalized child was purported by Nagera (1978). He suggested 11 types of preparation. They are as follows: (a) give the child information which includes a description of procedures and what to expect; (b) the child needs a reasonable time to deal with the information and prepare for it; (c) a visit to the hospital prior to admission may be helpful; (d) liberal visitation hours are essential; (e) small children must be allowed to take a familiar object from home to the hospital; (f) phone calls for hospitalized children are helpful; (g) the medical staff must carefully explain to the child the procedures and how much pain to expect; (h) in the cases of small children, especially, mother's presence during preoperative procedures is helpful; (i) restrict the child's movements as little as possible; (j) recreation and activities programs are a great asset; and finally, (k) weekly meetings for staff may be helpful in some hospitals.

Wolff (1969) advocated that the hospitalized child be encouraged to verbalize fears. The author cautioned that this may create short-term problems for the medical staff, but in the long run it would be beneficial to the child.

Besides Nagera (1978), several other researchers have expressed the need for preparation. Bellack (1974) believed children cope better if they are partners in the treatment. Clapp (1976) mentioned that school age and even preschool age children with cancer can be helped to understand what is happening to them. Wu (1965) contended that children need to know not only what will happen but how it will feel and what they can do to help.

In a survey, Peterson and Ridely-Johnson (1980) questioned 69 non-chronic care pediatric hospitals about hospital preparation for children and their parents. The survey indicated that 42.0% of the sampled offered all children preparation prior to hospitalization, 31.0% offered preparation for surgery, but only 19.0% had preparation for specific procedures. A majority of hospitals (74.0%) conducted some type of preparation program, most of these offering preparation programs for parents as well as children. Although the estimates varied greatly, an average of 42.0% of the children received some form of preparation.

Two studies showed children helping other children. Johnson et al. (1979) presented a case study showing that utilizing the resources of the children themselves is an effective way of dealing with some emotional stresses. One cancer child visits another cancer child. Nagera (1978) reiterated that it is surprising how much support children can offer each other. Riffee (1981) cautioned that when hospitals assign a school age child to a room with infants or much younger children, it can cause a threat to age appropriate behaviors. Thus, placing children of the same age in a double room may be more helpful than stressful.

Preparation for hospital experiences by modeling. Melamed and Siegel (1975) examined 60 children, ages 4 to 12 years, admitted to the hospital for elective surgery. Half of the children saw a peer modeling film depicting a child being hospitalized and experiencing surgery. The control group saw an unrelated film. Both behavioral and physiological measures of anxiety along with self reports revealed a significant reduction of both pre- and postoperative fear in the experimental group. The experimental group also displayed significantly fewer problems during posthospitalization. Vernon (1973) also used a peer modeling film for children, ages 4 to 9 years, who were about to have anesthesia. Approximately one-half to one hour before surgery, the experimental group saw children responding calmly to anesthesia induction. The children in the experimental group were significantly less anxious during the initial phases of induction, but this difference lessened as the procedure was administered.

Burling and Collipp (1969) monitored pulse rates of 13 children who were hospitalized from ages 15 months to 10 years. Use of a hypodermic needle was the most common cause of an increased heart rate. The admission examination was another stressful time. When parents were with the child, heart rates tended to decrease. Menke (1981) asked 50 hospitalized children to play a game developed by the researchers. Similar to Burling and Collipp's findings, 83.0% of the children in the Menke study perceived the hypodermic needle as the most stressful. Vernon (1974), in another study of films/modeling, assigned hospitalized children to one of three groups. One group saw a series of children receiving injections without any pain or fear. Another group saw a similar film, but this film showed children displaying negative reactions to the injections. The third group did not see either film. The observations of the children after the films revealed the greatest onset in the "no pain" movie group, with the least upset in the "pain" movie group. Vernon's findings seemed to support Johnson (1972) who hypothesized that discrepancy between expectations about sensations and experience during a threatening event results in distress. Melamed, Meyer, Gee, and Soule (1976) also reported a reduction in anxiety among hospitalized children who watched filmed modeling.

Preparation for hospital experience by puppet therapy. Puppet therapy has also been helpful in reducing anxiety in hospitalized children. Cassell (1965) worked with children, ages 3 to 11 years, who were going to have cardiac catheterization. The researcher presented a simple explanation of the procedure with puppets and play medical equipment. Children then could use the puppets and repeat the procedure. All questions were answered honestly. Sessions were held the day before catheterization and the day after. The children who had puppet therapy displayed less disturbance during catheterization and more willingness to return for further treatment than the controls. Johnson and Stockdale (1975) studied children, ages 5 to 8 years, admitted for elective surgery. One group of children saw a puppet show which the control group did not see. The Palmer Sweat Index was used to measure patient anxiety at four different times. The group which had received the puppet show exhibited significant reduction in anxiety from admission to the evening after surgery.

Siblings

Professional support. Craft (1979), Everson (1977), Issner (1972), and Poznanski (1969), getting their data from case studies or clinical observations, suggested interventions for the negative impact of hospitalization on siblings. These studies showed parents neglected the needs of the siblings.

Some studies indicate that professional mental health workers help siblings cope with their brother's or sister's illness; however, most often the parents alone are the ones that must deal with the emotional needs of the siblings (Feinberg, 1970; Sourkes, 1980).

Clapp (1976) noted that school nurses need to be informed as to how the ill child is adjusting so, in turn, the nurses can share this information with teachers and well siblings. Johnson et al. (1979) believed it important that members of the health care team speak to the siblings at a level they can understand about the cancer and its effects on the hospitalized patient. Binger et al. (1969) urged supportive therapy and counseling for patients and siblings as an essential part of total health care.

Medical staff can be helpful in providing assistance to parents on how to explain illness and death to their children (Grollman, 1970). Parents need to be supported so they can manage their own feelings, thus enabling the siblings to share concerns, fears, and questions with parents. It is helpful if well siblings participate in conferences with the physician and visit the patient in the hospital (Lansky, 1974; Lansky et al., 1976). Spinetta (1981b) warned that practitioners should not ignore the well siblings of childhood cancer because they live through the experience with the same intensity as the patient and parents.

Need for information and communication. Clapp (1976) urged the need for siblings of hospitalized cancer patients not to be left out in the health planning of the family. They need to know their role in the rehabilitation process and also the long-term plans. Factual information is needed not only for the parents and the hospitalized child but for siblings as well.

Open communication between well siblings and parents helps prevent later disturbed relationships (Binger et al., 1969; Kaplan et al., 1976). Koocher and O'Malley (1981) brought out the importance of parents communicating with the siblings in honest discussions. Such talks can help children deal with their own fears, allow expression of emotions, and assure the siblings that the parents will love and protect them. The healthy siblings also need continued parental attention and care as well as help in understanding the sick child's illness and behavior and changes in parent actions. Teyber and Littlehales (1981) believed from their experience that it is rare for siblings to be informed by parents of a terminal prognosis.

Spinetta (1981b) urged that professionals must continually remind families of the needs of well siblings. Siblings need to express feelings and receive answers to questions and need a continual updating of information about the patient and illness. Parents must be made aware of the siblings' needs and must support them.

In helping well siblings to cope with the reentry process, Kagen-Goodheart (1977) advised making it very clear to them that the returning brother or sister is still sick and will need extra attention. Also, acceptance of feelings of anger and jealousy toward the patient should be discussed. Well siblings should receive enough information to understand the medical situation and to assure them they will not also get sick. Well siblings should be helped to verbalize their fears. It may also be helpful to take the well sibling along to a minimally stressful outpatient day to help him/her become aware of what is happening to the ill child.

Koch et al. (1974) described the siblings' concerns as directly involved with the state of illness the patient is in. Siblings could handle their feelings about their brother or sister with leukemia and modify their behavior when parents had frequent open discussions, and the siblings were allowed to express their feelings (Heffron et al., 1973).

Gyulay (1975) suggested that siblings need a setting where they ask questions, seek answers, learn the truth, release their feelings, strike out, and act out. Siblings need to know their parents accept them and that they, too, are loved.

Hospital

Hospital environment. Some hospitals have recognized the psychosocial aspects of health care (Gogan, O'Malley, & Foster, 1977). Hartmann (1967) and Tonyan (1967) felt that encouraging parents to help with the care of their child and expanding visiting hours have made hospital environments more human. However, Mason (1965) was not impressed with the rate of these types of changes in American hospitals. "The gaps in the United States are surprisingly wide and resistance to change surprisingly strong" (p. 413). Schaffer (1967) was surprised at how American hospitals often lack living-in facilities.

Gogan, O'Malley, and Foster (1977) said:

> Clearly, change in hospital settings is a slow process and one that would cause difficult adjustment problems for the caregivers. If we are committed to treating the patient and the family as a whole, more adjustments will have to be made (p. 46).

Even though there is evidence that changes in hospitals are occurring slowly, King and Ziegler (1981) pointed out that there are still writers who have trouble comprehending why there is such a lack of correspondence between hospital procedures and research findings. Prugh and Jordon (1975), in a scathing review of the state of hospital affairs, said:

> These (research) findings have been repeatedly published and presented at meetings where pediatricians, nurses, and hospital administrators could learn about these advances. Yet, at the present time, there has been (very little) change in most hospital programs in the country (p. 210).

Prugh et al. (1953) completed one of the most comprehensive studies about preparing the environments of hospitalized children. The investigators studied 50 children, ages 2-12 years, who were at the hospital more than 48 hours. They instigated daily visiting, a play program, and preparation for traumatic or painful procedures. Another group, the control group of 50 children, was roughly matched on sex, age, length of stay, number of prior hospitalizations, and previous psychological adjustment. Data were gathered in the hospital at three weeks, three months, and later after discharge on aggression, anxiety, withdrawal, hyperactivity, sleeping, and feeding. Younger children, ages 2-5 years, exhibited the most extreme reactions. The experimental procedures had a positive effect on all ages both while in the hospital and afterwards. However, Prugh et al. noted that for children under 4 years of age, the experimental procedure was less effective.

Even though hospitals are slow to change, there are special programs for hospitalized children such as foster grandparent programs (Green, 1969; Hardgrove & Dawson, 1972; Issner, 1972) or community meal times in the hospital (Issner, 1972). Dombro (1970) advocated Child Life programs and believed the appropriate facilities, used knowledgeably, with concern for the child's and parent's needs, will help in the adjustment of both. A part of Child Life programs is a play program. Adams (1976) reported the importance of play for hospitalized children as did Tisza, Hurwitz, and Angoff (1970).

Issner (1972) noted that former hospital policies looked at parents as "hostile interlopers" to be kept at a distance from patients. Now rooming-in by parents is gaining more popularity. Brain and Maclay (1968) examined the rooming-in concept. In their study, all mothers wanted to room-in, but only one group was allowed to room with their children ages 6 years or under who were hospitalized for tonsillectomy or adenoidectomy. All results showed that the child's adjustment in the hospital was better, and the posthospital disturbance and postoperative complications were less in those children accompanied by their mothers.

Branstetter (1969) compared children whose mothers roomed-in, children who had all day mother substitutes, and children who were rarely visited. The children whose mothers roomed-in and children who had mother substitutes showed less upset behaviors than children in the mother absent group. Hardgrove and Rutledge (1975) demonstrated how rooming-in can be managed in the hospital even without proper facilities.

Hodapp (1982) also suggested rooming-in for parents, along with liberal visiting rights, primary care nursing, having pictures of the family in the child's room, and having play periods in a hospital playroom. Hodapp also advocated preparation for treatment and procedures in the hospital, flexibility in scheduling to meet the child's needs, counseling for parents if they wish, and phone calls or tape recorded messages from friends and siblings. Further, Spivack (1979) suggested tape recorded messages and the familiar sounds of the house to comfort the very young hospitalized child.

Visitation. Besides rooming-in by parents or a foster grandparent program for hospitalized children, visitation in the hospital needs to be examined more closely.

Visiting policies of hospitals have long come under question. Edleston (1943) was a strong advocate for liberalizing pediatric visiting policies when short weekly visits were the norm. Sir James Spence was also a vocal campaigner for changes in the way children's hospitals were run.

He took it for granted that major disturbances in children were due to separation from mother (1947). Burling and Collipp (1969) mentioned a study in England in 1959 where unlimited visiting was requested. Several studies already mentioned have encouraged liberalizing visiting or special visitation programs (Brain & Maclay, 1968; Branstetter, 1969; Dombro, 1970; Hardgrove & Dawson, 1972; Hartmann, 1967; Hodapp, 1982; Nagera, 1978; Prugh et al., 1953; Riffee, 1981; Tonyan, 1967).

Sibling visitation has been proposed as a means of reducing stress not only for the hospitalized child but also for the well sibling(s) (Caldwell, 1982). Advocates of sibling visitation, however, rely on opinions rather than on facts since there are no reported studies to indicate benefit to the sibling(s) or the hospitalized child (Caldwell, 1982; Shuler & Reich, 1982; Wallinga, 1982). The possibility of negative repercussions of visitation has been discussed by Caldwell (1982). Possible problems were as follows: increase in disease; interference with patient care; crowded hospital spaces; and the possibility of routine hospital practices being misperceived by the sibling(s), which, in turn, may cause more fear of the hospital than before visitation. The above issues remain uninvestigated.

An existent barrier to sibling visitation as a possible preventative therapy is the assumption that the children might possibly transmit diseases to patients (Caldwell, 1982; Shuler & Reich, 1982). Shuler and Reich (1982), in a series of mail surveys to state health departments, pediatric hospitals, pediatricians, and epidemiologists, explored the current situation of liberalizing visitation policies to include siblings of hospitalized children. The researchers determined that there was a growing trend toward lifing restrictions that bar siblings from visiting. However, Shuler and Reich (1982) caution that even though 5 of the 9 pediatric hospitals responding to one of the surveys concluded there was no increase in nosocomial infection, there had been no known formal studies on the increase in epidemiology in these hospitals. One of the few studies which actually examined the possibility of transmitting disease by visitation was conducted by Umphenour (1980). This investigation focused on the bacterial colonization in 403 neonates who had been visited by their siblings soon after birth. Results showed there was no increase in bacterial colonization due to postpartum sibling visitation.

Riffee (1981), in a study already discussed, raised the question that if surgical children experience a decline in self-esteem derived from peer/social interactions, maybe these school age children need peer contacts during and right after hospitalization. Hospital visiting policies often exclude children under 14 years of age. Consequently, the hospitalized school child is isolated from his peers at a time when the patient is already anxious about the ability to return to a peer group.

Lord and Schowalter (1979) investigated visiting patterns on an adolescent ward. Subjects were 100 girls and 100 boys, ages 11-13 years, with illnesses that ranged from moderate to severe. The 200 patients averaged more than four visitors a day, and 93.0% of the mothers and 67.0% of the fathers came on a given day. As length of hospitalization increased, numbers of visitors other than parents decreased. The 11-year-olds received one-third fewer visitors than the 13-year-olds. The number of siblings or other relatives was about 34.0% of all visitors for both

The difference in the groups was that friends were predominant visitors of 13-year-olds. Mothers and fathers visited children of both sexes equally and averaged an hour longer with the sons. Sisters seemed to visit more than brothers, and both groups were visited more often by same sex peers. Children with mild illnesses averaged one more visitor per day than those categorized as more seriously ill.

Concerning preferences, Lord and Schowalter found the majority (52.0%) of the hospitalized children felt they had enough visitors per day (mean = 4.6). Forty-three percent of the children who had 3.4 visitors per day wished they had more. Visits of one to two hours seemed to be most appreciated. Twenty-six percent of the 200 teenagers preferred parents to visit, with another 19.0% specifically choosing mothers and 1.5% choosing fathers. The older patients favored friends over parents. The author made it clear that visitors to the adolescents were crucial to their morale. Patients often tried to cheer up worried parents who attempted to "baby" them. Siblings and friends who could accept the patient in spite of the illness were great morale builders and helped them keep contact with the outside world.

Even with increased advocates for visitation, the fact remains that sometimes hospitalized children do not receive many, if any, visitors. Cancer is not only a mysterious but also often fatal disease, and friends may often shun the child with cancer for fear they will be affected or feel uncomfortable about the child's questionable future (Gogan, O'Malley, & Foster, 1977). It was noted that even medical staff such as doctors and nurses along with family members may avoid a child with cancer.

As mentioned in an earlier section, Spinetta, Rigler, and Karon (1974) had children with leukemia place dolls in a play hospital room. The dolls represented the patient, a doctor, nurse, and mother. The leukemic children tended to be isolated, and the patient's interpersonal distance was significantly greater than the control children scores as shown by the placement of the dolls. Kaplan et al. (1973) cited a case example where parents of a 3-year-old child dying of cancer abdicated their parental responsibility by not visiting their child because it caused them too much emotional pain.

Lord and Schowalter (1979) also interviewed 50 fathers and 50 mothers of 11 and 13 year olds that were hospitalized. Eighty-six percent of the mothers visited because they were genuinely concerned. However 7 of 50 mothers viewed visiting as motivated by guilt or duty. Most mothers were very empathic towards their children and tried to conceal their anxiety. However, the seven mothers already mentioned were often extremely fussy, self-centered, and outright hostile. A little over 50.0% of the visiting fathers said they were motivated by concern and affection. The chief motivation cited by the other group of fathers was that it was their duty or moral obligation. Some fathers seemed to offer real support to their children while others manifested their depression and discomfort by being bored, restless, and irritable. Fathers tended to blame their anxiety on the fact of visiting rather than their child's condition. Fathers could express more anger and showed more relief at leaving the hospital than mothers. The authors felt fathers used obvious denial as a way to leave emotionally and noted three times as many fathers as mothers described their child with unrealistic optimism.

Bowlby (1966) and Robertson (1970) have demonstrated the value of parents to the pediatric units. Bowden (1979) cited a community hospital in a large southwestern city that changed to family center care. In pediatrics, parents are urged to visit as often as they want and, when a child is hospitalized for a long time, arrangement for sibling visitation is made. They also have a play program and separate adolescent ward.

Because visitation is so important, more attention needs to be focused on the issue. Learning how to support and facilitate visiting is an important area that health care professionals need to address (Caldwell, 1982; Lord & Schowalter, 1979; Wallinga, 1982).

In summary, research shows that ameliorative efforts must be recognized as a necessity in the lives of families with hospitalized and ill children. Since parents, ill children, and siblings all have their own needs, help can be given through intervention, preparation, and group programs. While some initial efforts have been made, it appears that hospital professionals must become more aware of ameliorative opportunities with families.

Conclusions from the Review of Literature

Literature available on siblings of the hospitalized child is limited. Data gathered on siblings per se had to be gleaned from research where siblings were not the dominant topic. What findings have been obtained have often come from parent reports in studies where sample size was small and where the studies did not lend themselves to comparisons. The literature that does exist tends to reveal a void in indicating if there is agreement between the perceptions of the parents and the well siblings about the hospitalization of the child. The review of literature also indicates that hospitalization frequently appears to affect the family system causing more disruption in some families and family members than in others. A recurring theme points out that siblings are an important component of the family system and should not be neglected when studying the effects of the child's hospitalization on the family. A vital step in that effort seems to be encouraging siblings to share their feelings and ideas.

METHODOLOGY

Purpose

The main purpose of the present study is to investigate similarities and discrepancies of perceptions of well siblings and parents concerning an ill child's hospitalization. The following major family areas were identified for study: (a) family maintenance; (b) family relationships; (c) family communication; (d) health attitudes; and (e) perceptions of siblings, parents, and the hospitalized child.

Instrumentation

The researcher did an extensive review of the literature concerning the effects hospitalization of a child had on family members. While various factors seemed to affect the family's adjustment to a child's hospitalization, 12 recurring broad content areas surfaced. These issues were as follows: (1) parent employment; (2) financial issues; (3) transportation; (4) caregiving; (5) family tasks; (6) family relationships; (7) affection in the family; (8) family communication; (9) health attitudes; (10) knowledge of illness; (11) family stress; and (12) perceptions of family members. Once these issues were delineated, specific questions were generated for both children and parents under each one.

Since subjects ranged in age from 6 to 15 years, the researcher decided that the most practical instrumentation for children would be a structured interview (individually administered questionnaire). The instrument developed for parents was a paper-pencil self-administered questionnaire which paralleled the well child's structured interview.

The formulation of the questionnaire items required numerous revisions. The Questionnaire for Well Siblings was revised 10 times while the Questionnaire for Parents was revised 7 times. Each revision of the questionnaire was piloted on surrogate subjects. The format of the revisions varied with some questionnaires being completely open-ended, while others were close-ended or a combination thereof. Shortening the questionnaire and clarity of the questions were prime considerations in revising the questionnaires.

The final well sibling structured interview questionnaire was a combination of both open-ended and close-ended questions. The 135 item interview questionnaire required between 30 to 90 minutes to administer, but most interviews took approximately 40 minutes.

The Questionnaire for Well Siblings began with three simple questions intended to make the subject feel at ease. After these "warm up" items, attention was directed to a section of general open-ended questions. These questions increased in specificity and were designed to get at the saliency of how soon the well siblings would mention the hospitalization of their brother or sister, thus, an indication of sibling concern about hospitalization. Following these questions, the well sibling instrument had sections on (a) household and caregiving issues, (b) family relationships, (c) family communication, (d) health attitudes, (e) well child's perception of parents, (f) knowledge of illness, (g) well child's perception of self, (h) well child's perception of the hospitalized child, and (i) added hospital services.

Since the researcher did not want to influence the child's response to the close-ended questions, the format of the instrument was developed so that a general open-ended question usually preceded the close-ended questions in the above sections. When responding to the general open-ended questions, the subjects often answered the specific close-ended question or questions. If the close-ended questions were answered, the interviewer marked the close-ended question answer and preceded to the next question. If the interviewer had any doubt as to whether the general response answered a specific close-ended question, the interviewer read the close-ended question. Based on this format of asking the open-ended question before the close-ended question, the researcher is fairly certain that the interviewer would not prejudice the child's response. The Questionnaire for Well Siblings is found in Appendix A.

The questionnaire given to the parents of the well children in this study was a paper-pencil instrument containing 83 items with 79 close-ended questions and 4 open-ended questions. Most parents were able to complete the questionnaire in 20 minutes. Unlike the Questionnaire for Well Siblings, the Questionnaire for Parents was self-administered.

The Questionnaire for Parents was designed to include the following sections: (a) household and caregiving issues; (b) family relationships; (c) family communication; (d) health attitudes; (e) well child's perception of parents; (f) knowledge of illness; (g) well child's perception of self; (h) well child's perception of the hospitalized child; (i) family stress; and (j) hospital services. See Appendix B for a copy of the Questionnaire for Parents used in this study.

Even though the format for the two questionnaires differed, the instruments were designed so that both well siblings and parents were asked matched close-ended questions on 53 items. These matched items allowed the researcher to compare the responses of well siblings and parents. Due to the researcher's prime interest of investigating similarities and discrepancies of perceptions between well siblings and parents concerning an ill child's hospitalization, it is on these items that the researcher has based her study. The discrepancy between the number of items used in the present study and the actual number of items data were collected on is due to the researcher's interest. Because of the great difficulty of identifying and contacting subjects, the researcher collected data for related studies.

A third questionnaire for the hospitalized child was developed for this study but was not used. The Questionnaire for the Hospitalized Child contained the same content sections as did the Questionnaire for Well Siblings.

This study was approved by the Human Subjects Committees of both Iowa State University and the University of Georgia.

Interviewers

The subjects for this study were interviewed by four trained female interviewers: a faculty member and three senior students in the College of Home Economics at the University of Georgia. Training for interviewing the subjects consisted of a two-hour individual demonstration session in which the researchers familiarized the interviewer with the two questionnaires. They also practiced their interviewing skills on surrogate subjects provided by the researcher.

Subjects

Children

Subjects for this study were 31 children, 13 boys and 18 girls, who had a sibling hospitalized in either the pediatric unit at Athens General Hospital or St. Mary's Hospital in Athens, Georgia. Both pediatric units were small, under 25-bed secondary care units. The hospitals make initial diagnoses and are equipped to handle most emergencies. Severe medical emergencies and illnesses requiring extended care are transferred to a larger pediatric facility in Atlanta, Georgia.

The children selected for the study had to be between the ages of 6 to 15 years and have a hospitalized sibling who met the following requirements: (1) age between 3 and 15 years; (2) length of hospitalization to be two or more days; and (3) no major impairments other than the one for which the child was hospitalized. Another criterion for sample selection was that no other family member had been hospitalized for more than two days during the year prior to the investigation.

Parents

Subjects were 42 parents of the well and hospitalized children. Of the 42 parents, 26 were mothers and 16 were fathers. There were 16 mother-father pairs out of a possible 20 pairs with 6 mothers participating as single parents.

Data Collecting Procedures

In order to obtain subjects, meetings were held with the Maternal and Child Coordinator at Athens General Hospital and the Director of Nursing at

St. Mary's Hospital in Athens, Georgia. After these initial contacts, a progressive series of meetings culminated in permission from individual pediatricians at St. Mary's Hospital and from the Hospital Administrator at Athens General Hospital.

After all arrangements had been made with the hospitals, the interviewers began making three to four trips per week to the hospitals for a ten-month period. Availability of patients, records, and families was dependent on the cooperation of hospital personnel and the hospital's census.

In order to identify possible subjects, the interviewers arranged to obtain the following information from the pediatric census: identification of whether or not the hospitalized patient had a well sibling that met the research criteria; identification of the length of possible hospitalization; identification of the category of illness; and identification of a means to contact parents.

When a family was identified as meeting all the research criteria, the interviewer contacted the parents either in person or by phone to explain the purpose of the study to them. If the parents consented to participate in the study and were willing to sign the informed consent (Appendix C), an appointment was arranged whereby the interviewer would go to the parents' home and administer the questionnaire to the well sibling closest in age to the hospitalized child. If meeting in the parents' home was not convenient for the parents, a mutually agreed upon location was found where the interviewer could interview the child. The interviewer attempted to interview the well children on the second or third day of the ill child's hospitalization; however, this was not always feasible due to the difficulty in contacting some families and the disrupted schedules occurring in many of the families.

After permission from the parents was obtained and the well child was made available for the interview, the study was explained to the child. Children, ages 14 years or older, were asked to sign an Informed Consent, while children under age 14 years were asked to give verbal permission (Appendix D). All interviews were tape recorded unless one of the parents, the well child, or the hospital administration objected. Tape recordings were made on 18 of the 31 well children. These tape recordings provided a means of clarifying well siblings' responses if necessary. Interviews were conducted with only the interviewer and the well child present.

Upon completion of the well sibling interview, parents were asked to fill out a Parent Information Form (Appendix E) and a Parent Questionnaire. A cover letter explaining the questionnaire was utilized (Appendix F). If parents were unable to read, the interviewer read aloud the questions. A stamped, self-addressed envelope was provided so that parents who could read could complete the questionnaire and return it by mail. If, after four days, the Parent Questionnaire was not returned to the interviewer, follow-up phone calls were made.

Statistical Procedure[1]

Upon completion of the data collection, the 53 responses were coded for key punching. The first computer data print-out was for frequencies

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[1] Dr. Leroy Wolins, Professor, Iowa State University, served as the statistical consultant for the study.

and percentages of the closed-ended items on the two questionnaires and the parent information form. This enabled the researcher to check the feasibility of the planned statistical analysis. The open-ended responses were also grouped at this time.

Two methods of computing were applied to the data. That is, with a 2 x 2 table, the traditional chi-square was utilized; with all other tables the diagonal totals (agreement) was taken against all other cells (disagreement) (Light, 1971). These chi-square procedures were applied to the 53 close-ended items on the well sibling and parent questionnaires and are noted in Tables 13 and 14 of Chapter IV. This enabled the researcher to examine the agreement and disagreement between the responses of the (1) well siblings and mothers, (2) well siblings and fathers, and (3) mothers and fathers. It was not possible to present all data for the reader to compute his/her own chi-squares because the number of subjects responding varied on some questions. It also would be impossible for the reader to identify the mother-father pairs or the parent-sibling pairs.

To determine the saliency of the hospitalization issue, the researcher tabulated how soon the well siblings mentioned the hospitalization of their brother or sister when responding to a series of questions, thus, permitting the researcher to investigate sibling concern about the hospitalization.

FINDINGS

This exploratory study was designed to investigate the perceptions of both the well siblings and parents concerning an ill child's hospitalization and their possible similarities and discrepancies of perceptions.

The purpose of this chapter is to examine the findings of the statistical analysis of data collected in this investigation. Findings are organized and presented under the following major headings: demographic data; saliency questions; null hypotheses; and scattergram findings.

Demographic Data

Subjects

Children. Subjects for this study were 31 children who had a sibling hospitalized in either of two hospitals in Athens, Georgia. The well siblings ranged in age from 6 to 15 years and the hospitalized siblings from 3 to 16 years. The condition of health of the hospitalized children was classified as acute (51.6%) or chronic (48.3%), and most of these children remained in the hospital no more than five days (67.7%). The well sibling was usually interviewed on the second or third day (61.3%) of the ill child's hospitalization. Most of the well siblings interviewed were the oldest child in the family (54.8%) while the predominant group of hospitalized children were described as the youngest (45.2%).

Parents. Subjects were 42 parents of the well children. Of this number, 26 were mothers and 16 were fathers. Most parents were married (80.6%) and resided less than 10 miles from where their child was hospitalized (45.2%). Most mothers were over 31 years of age (83.9%), had completed high school or an advanced degree (77.5%), and were employed either full or part time outside the home (58.0%). Most fathers were over 31 years of age (88.0%), had completed high school or an advanced degree (76.0%), and were employed outside the home (88.0%). Family size was usually four members (41.9%) or five members (38.7%). See Appendix G for total breakdown of demographic data gathered.

Responses to each of the 53 questions for the well siblings, mothers, and fathers are listed in percentages in Appendix H. Due to the fact that the sample size of the three family groups was not equal, percentages were used rather than numbers of subjects responding to each answer of the questions.

Saliency Questions

To measure sibling concern about the hospitalization, nine open-ended questions which increased in specificity were designed to measure the saliency of how soon the well siblings would mention the hospitalized child or the hospitalization (Appendix I). The following is a listing as to when the well sibling first made reference to the hospitalized child or the hospitalization: first question 43.33% (N=12); second question 16.67% (N=5); third question 16.67% (N=5); fourth question 10.00% (N=3); fifth question 3.33% (N=1); sixth question 3.33% (N=1); seventh question 0.00% (N=0); eighth question 0.0% (N=0); and the ninth question 6.67% (N=2). One of the 31 well siblings was not included in the measurement because the child had expressed concern about the hospitalized child to the interviewer before the official interview began. The well siblings' early reference to the hospitalized child or hospitalization seems to indicate that the hospitalization is an issue that is in the forefront of their thoughts.

Null Hypotheses

In the material that follows, tabular and written presentations related to specific null hypotheses will be offered. A significance at or beyond the .05 level was necessary for rejection of a given null hypothesis. Discussion of these findings is presented in the following chapter.

Major Hypothesis I. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family maintenance issues.

Hypothesis 1a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on household issues.

Chi-square data for family members' perceptions are presented in Table 1. There were two significant chi-squares when comparing mother and father data and no significant chi-squares between mothers and well siblings or fathers and well siblings. The first significant item indicated perceptual agreement by parents concerning money discussions since their child's hospitalization. The second significant item indicated parental agreement on travel arrangements to and from the hospital. Thus, in 2 out of 9 instances, Null Hypothesis 1a was rejected.

Table 1. Chi-square values for household issues

Question	Mother Well sibling	Father Well sibling	Mother Father
1	1.2084	.1357	.1357
2	.1590	.4530	3.6850*
3	1.0066	.0157	3.0745*

*$p < .05$.

Hypothesis 1b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on caregiving issues.

To test the hypothesis about the caregiving issues, six chi-squares were computed. No significant chi-square values were reported for either the father-well sibling or mother-father data (Table 2). The two significant chi-squares for mother-well sibling data indicated agreement on child care and where that care was taking place. Therefore, in 2 out of 6 instances, Null Hypothesis 1b was rejected.

Table 2. Chi-square values for caregiving issues

Questions	Mother Well sibling	Father Well sibling	Mother Father
4	2.7429*	.3287	.1021
5	9.0955*	.1357	.0018

*p < .05.

Hypothesis 1c. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family tasks.

This hypothesis attempted to establish whether or not there was agreement between family members' perceptions of family tasks. For mother-well sibling data, three of five chi-squares were significant; however, for the father-well sibling and mother-father responses, no significant chi-squares were found (Table 3). The three significant items dealt with whether or not the well siblings' chores increased, if they had to do more housework, and if they had more work in caring for themselves. Thus, in 3 out of 15 instances, Null Hypothesis 1c was rejected.

Table 3. Chi-square values for family tasks

Question	Mother Well sibling	Father Well sibling	Mother Father
6	5.2267*	.5385	.0632
7	2.3392	.6571	.3714
8	3.4667*	.4000	.0714
9	.0181	.0350	.3714
10	3.7438*	.2308	.0050

*$p < .05$.

To summarize Major Null Hypothesis I, 7 of 30 possible chi-squares were significant. Five of the significant findings indicated mother-well sibling agreement while the other 2 significant findings indicated mother-father agreement.

Major Hypothesis II. There is no agreement between family members' perceptions concerning the effect hospitalization has on family relationships.

Hypothesis 2a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has the affections shown in the family.

One significant chi-square was computed for mothers and well siblings and one significant chi-square for the mothers and fathers (Table 4). Agreement for mothers and well siblings was on the question "Since the hospitalization does the family like each other or care about each other more, same or less?" Mothers' and fathers' agreement was on the question

"Since the hospitalization, do you and your other children get along better, same or worse?" Thus, in 2 out of 6 instances, Null Hypothesis 2a was rejected.

Table 4. Chi-square values for affection shown in the family

Question	Mother Well sibling	Father Well sibling	Mother Father
16	5.5616*	.3750	.0250
17	.4800	1.1211	3.6575*

*p < .05.

Hypothesis 2b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship with the well sibling.

Hypothesis 2c. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship with the hospitalized child.

Hypothesis 2d. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the parents' relationship.

Null Hypotheses 2b, 2c, and 2d address themselves to the effect hospitalization of an ill child has on the parents' relationship with each other, with the well sibling, and with the hospitalized child. No significant chi-squares were found for any of these hypotheses (Tables 5, 6, and 7). Evidence presented was not sufficient to reject the Null Hypotheses 2b, 2c, and 2d.

Table 5. Chi-square values for the perceptions of the parents' relationship with the well sibling

Question	Mother Well sibling	Father Well sibling	Mother Father
18	2.2494	.0979	2.2234
19	.6272	.5417	.0286

Table 6. Chi-square values for the perceptions of parents' relationship with the hospitalized child

Question	Mother Well sibling	Father Well sibling	Mother Father
20	.7090	.3429	.2417
21	.4750	.3500	.2571

Table 7. Chi-square values for the perceptions of the parents' relationship

Question	Mother Well sibling	Father Well sibling	Mother Father
22	.4957	.0952	.9418

To summarize Major Null Hypothesis II, 2 of 21 chi-squares were significant. One significant chi-square was found for the mother-well sibling data, while the other significant chi-square was found for the mother-father data.

Major Hypothesis III. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family communication.

Chi-square results between the family members' perceptions are presented in Table 8. One significant chi-square was found for father-well sibling data. Also, for both the mothers and well siblings and mothers and fathers, two of the three possible chi-squares proved significant. The item that was significant for all three groups concerned who told the well child about the hospitalized child's illness. The one item that was significant for both the mother-well sibling and mother-father data was "Does the well child wish his/her family would talk about the sick child being in the hospital more, same, or less?" Thus, in 5 out of 9 instances Null Hypothesis III was rejected.

Table 8. Chi-square values for family communication

Question	Mother Well sibling	Father Well sibling	Mother Father
23	.3400	.8654	.0442
24	5.9980*	.6828	6.8686*
40	14.5005*	7.2290*	8.5937*

*p < .05.

Major Hypothesis IV. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the health attitudes of the well sibling.

This hypothesis examines the agreement of family members' perceptions concerning the health attitudes of the well sibling. One significant chi-square for the mother-father data was computed (Table 9). The item that was found to be significant asked whether parents thought the well sibling thought about getting sick and possibly going to the hospital more, same, or less.

It was impossible to actually compute chi-squares for some of the items for this null hypothesis. On some items, there was a 100% agreement which indicated rejection of the Null Hypothesis but not by chi-square calculations. When an item is listed 1 cell, it means family members agree 100%. When an item under this hypothesis is listed 2 cells, it means that one group responded with either of two choices while the other group responded with only one choice of answers, i.e., mothers responded with either a yes or no, while the well sibling only responded with a no. Well siblings and mothers all agreed that since the hospitalization the well siblings had neither infections nor rashes. On the other hand, well siblings and fathers all agreed that since the hospitalization the well siblings had no infections, no rashes, and no other ailments other than those listed in the questionnaire. Mothers and fathers had the most agreement among family groups. They all reported agreement that since the hospitalization the well sibling had no infections, no headaches, no stomachaches, no rashes, and no other ailments other than those listed in the questionnaire. Therefore, in 15 out of 21 instances Null Hypothesis IV was rejected.

Table 9. Chi-square values of the perceptions of the health attitudes of the well sibling

Question	Mother Well sibling	Father Well sibling	Mother Father
25	.0906	2 cells*	.8667
26	1 cell-all no*	1 cell-all no*	1 cell-all no*
27	.7273	2 cells*	1 cell-all no*
28	2 cells*	2 cells*	1 cell-all no*
29	1 cell-all no*	1 cell-all no*	1 cell-all no*
30	2 cells*	1 cell-all no*	1 cell-all no*
31	.5953	.3804	11.3760*

*$p < .05$.

Major Hypothesis V. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on family members.

Hypothesis 5a. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the well siblings' perception of their parents.

Chi-square values are presented in Table 10. Four of the 10 items for mothers and well siblings reached significance. These items indicated agreement on how busy, tired, and worried Mother seemed and how worried Father seemed. Looking at the father-well sibling data, only one item which asked whether Mother seemed more, same, or less worried reached significance. In assessing the mother-father data for this hypothesis, 4 of the 10 items were significant. These items indicated agreement on how happy Mother seemed and how busy, happy, and worried Father seemed. Thus, in 9 out of 20 instances Null Hypothesis 5a was rejected.

Table 10. Chi-square values of perceptions of how the well siblings perceive their parents

Question	Mother Well sibling	Father Well sibling	Mother Father
32	2.9697*	.3385	.7582
33	3.9610*	.9315	.0470
34	1.8533	.3390	4.2855*
35	4.4382*	2.9343*	1.6500
36	.3733	.4126	.1678
37	.2178	.0230	.0105
38	2.1063	.8698	10.9454*
39	5.6203*	.7426	.1648
52	.4861	.8346	2.9630*
53	.4039	.2293	5.0100*

*p < .05.

Hypothesis 5b. There is no agreement between family members' perceptions concerning the effect hospitalization of the ill child has on the well siblings' perception of themselves.

In contrast to Null Hypothesis 5a, Null Hypothesis 5b directs itself specifically to family members' perceptions of how the well siblings perceived themselves. There is only one significant chi-square noted for the mother-well sibling data and no significant chi-squares reported for either the father-well sibling data or the mother-father data (Table 11). The only item that was significant for the mother-well sibling responses asked whether the well sibling wished he/she had not fought so much with the hospitalized child. No chi-square could be calculated on one question of the father-well sibling data concerning whether or not the well child was angry about the attention the hospitalized child received. It must be noted that on this question all well siblings said "no" and all but one of the fathers responded with "no." Thus, in 2 out of 33 instances the Null Hypothesis 5b was rejected.

Table 11. Chi-square values of perceptions of how the well siblings perceive themselves

Question	Mother Well sibling	Father Well sibling	Mother Father
41	.0434	.0952	.3500
42	1.6341	.6958	.1181
43	.6944	.7582	.1875
44	0.0000	.2418	.0028
45	.6494	.8000	.0714
46	.0026	.6286	.4500
47	3.7152*	.3462	.0357
48	.8057	.2667	.9375
49	.0416	2 cells*	.0625
50	.8393	.8125	.1250
51	.4136	.6346	.0769

*$p < .05$.

Hypothesis 5c. There is no agreement retrospectively between family members' perceptions concerning what the relationship between the well sibling and the hospitalized child was previous to hospitalization.

This hypothesis, as distinguished from Null Hypothesis 5a and 5b, investigated family members' perceptions as to what the relationship was like between the well sibling and hospitalized child previous to hospitalization. No significant chi-squares were reported for either the mother-well sibling or father-well sibling data (Table 12). The one significant chi-square for the mother-father data indicated agreement on how much the well sibling and hospitalized child argued. Therefore, in 1 out of 15 instances Null Hypothesis 5c was rejected.

Table 12. Chi-square values of the perceptions of the well sibling's and hospitalized child's relationship previous to hospitalization

Question	Mother Well sibling	Father Well sibling	Mother Father
11	2.1600	.0157	1.0826
12	.0550	.2334	2.5414
13	.0593	1.5686	1.0158
14	1.5400	.8217	.0039
15	1.0490	.8905	3.5320*

*$p < .05$.

To summarize Major Null Hypothesis V, 12 of 78 possible chi-squares were significant. Five significant chi-squares indicated mother-well sibling agreement, two significant chi-squares indicated father-well sibling agreement, while five significant chi-squares indicated mother-father agreement.

Tables 13 and 14 summarize the agreement between family members' perceptions of the hospitalization experience on 53 items from the well siblings' and parents' questionnaires. The type of chi-squares calculated on each item is also listed. These tables illustrate that there is some agreement between family members. The total number of significant chi-squares obtained was 42 out of the 159 possible instances (agreement combinations). Mother and well siblings agreed on 17 of 53 items, fathers and well siblings agreed on only 9 of 53 items, and mothers and fathers agreed on 16 of 53 items.

Table 13. Summary of the significance and types of chi-square tests[a] for items 1-27

Question	Mothers Well siblings	Fathers Well siblings	Mothers Fathers
1	RCS N=26	F N=16	F N=16
2	D N=24	D N=15	D* N=16
3	D N=26	D N=16	D* N=16
4	RCS* N=26	F N=16	F N=16
5	RCS* N=25	F N=16	F N=16
6	RCS* N=24	F N=15	F N=16
7	RCS N=25	F N=15	F N=15
8	RCS* N=26	F N=16	F N=16
9	F N=19	F N=13	F N=15
10	RCS* N=25	F N=15	F N=14
11	D N=26	D N=16	D N=16
12	D N=26	D N=16	D N=16
13	D N=26	D N=16	D N=16
14	D N=26	D N=16	D N=16
15	D N=25	D N=16	D* N=15
16	D* N=26	D N=16	D N=16
17	D N=15	D N=12	D* N=13
18	D N=26	D N=16	D N=16
19	F N=19	F N=16	F N=15
20	RCS N=25	F N=15	F N=16
21	F N=19	F N=16	F N=15
22	D N=19	D N=15	D N=16
23	D N=25	D N=15	D N=16
24	D* N=23	D N=15	D* N=15
25	RCS N=25	2-C[b]*N=16	F N=15
26	1-C[c]*N=24	1-C* N=16	1-C* N=15
27	RCS N=24	2-C* N=16	1-C* N=15

[a] RCS = raw chi-square; F = Fischer's exact test; D = diagonal chi-square.

[b] 2 cells.

[c] 1 cell.

*Significant.

Table 14. Summary of the significance and types of chi-square tests[a] for items 28-53

Question	Mothers Well siblings	Fathers Well siblings	Mothers Fathers
28	2-C[b]*N=24	2-C* N=16	1-C[c]*N=15
29	1-C* N=24	1-C* N=16	1-C* N=15
30	2-C* N=5	1-C* N=2	1-C* N=8
31	D N=22	D N=15	D* N=14
32	RCS* N=24	F N=15	F N=15
33	D* N=24	D N=15	D N=15
34	D N=24	D N=15	D* N=15
35	D* N=25	D* N=16	D N=15
36	F N=17	F N=13	F N=15
37	F N=17	F N=14	F N=14
38	D N=18	D N=14	D* N=14
39	D* N=17	D N=14	D N=14
40	D* N=26	D* N=16	D* N=16
41	RCS N=25	F N=15	F N=16
42	RCS N=25	F N=16	F N=16
43	RCS N=25	F N=15	F N=16
44	RCS N=25	F N=15	F N=16
45	RCS N=25	F N=15	F N=16
46	RCS N=25	F N=15	F N=16
47	RCS* N=25	F N=16	F N=16
48	RCS N=25	F N=15	F N=16
49	RCS N=26	2-C* N=16	F N=16
50	RCS N=26	F N=16	F N=16
51	RCS N=25	F N=16	F N=15
52	D N=26	D N=16	D* N=16
53	D N=18	D N=15	D* N=15

[a] RCS = raw chi-square; F = Fisher's exact test; D = diagonal chi-square.

[b] 2 cells.

[c] 1 cell.

*Significant.

Scattergram Findings

Three scattergrams comparing the responses between the mothers and well siblings, fathers and well siblings, and fathers and mothers are presented in this section. Since the items that are plotted do not have the same number of possible choices of responses, it was necessary to utilize two plotting schemes. On all items which had two possible choices, the first response was used. Thus, when comparing the responses of two individuals on an item that had only two possible responses, the same 1-1 cell was utilized (see Figure 1).

		1. Yes	2. No
Mothers	1. Yes	Cell plotted	
	2. No		

Figure 1. Scattergram plotting procedure

On all items which had three or more possible responses, the extreme cells were examined, i.e., on a 3 x 3 table the 1-1 cell or the 3-3 cell would be utilized, whichever was the largest and closest to 50%. This same format was used with 4 x 4, 5 x 5, and 6 x 6 tables. These two methods for plotting agreement are indicated on each scattergram. When examining the scattergrams, the plotting points that cluster around the 45° line indicate agreement between respondents.

In Figure 2, a comparison of the responses between mothers and well siblings are plotted. The most evident results seen from this figure are that 1) there appears to be little agreement between the mothers' and well

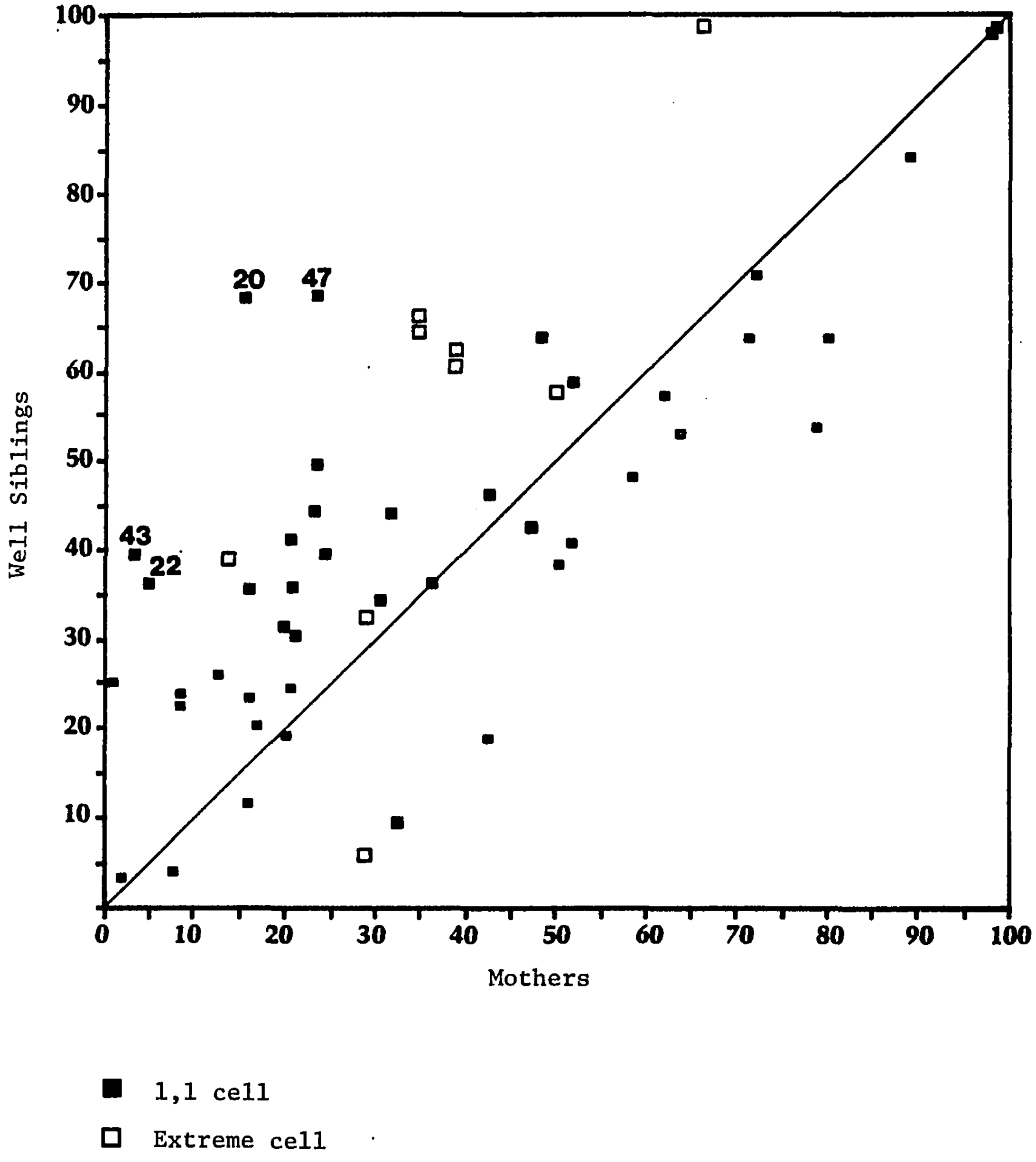


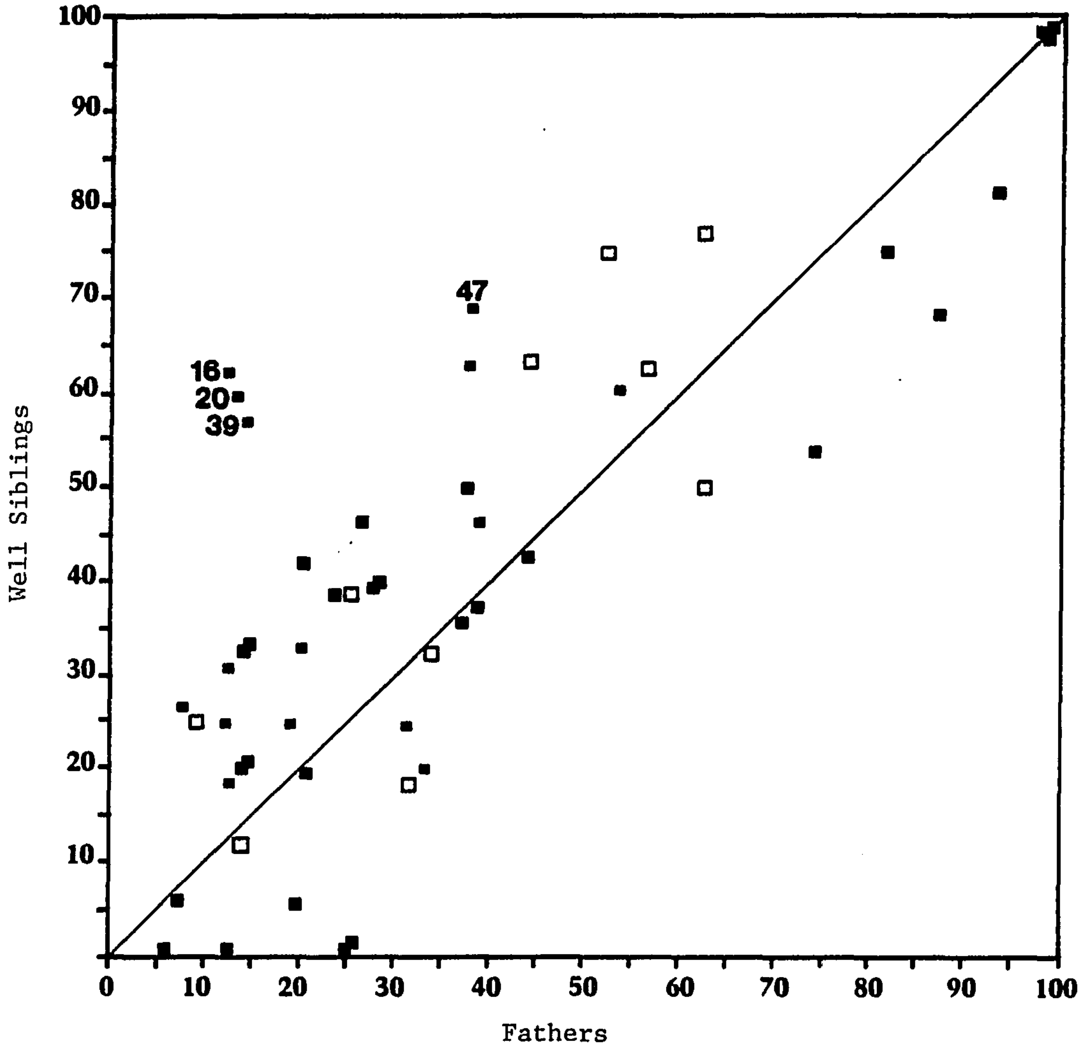
Figure 2. Comparison of the responses between well siblings and mothers

siblings' responses and 2) there seems to be a trend for the well siblings to indicate more concern than the mothers. This is indicated by the plotted points in the upper left quadrant of the 45° line.

Four items on which the mothers and well siblings particularly disagreed were: item 20; item 22; item 43; and item 47. Item 20 indicated that the well siblings perceived mother and the hospitalized child getting along better than mothers perceived the situation. On item 22, well siblings perceived that their parents got along better than the mothers perceived their relationship with the spouses to be. On item 43, the well siblings were more afraid of getting sick than the mothers perceived them to be. On item 47, more well siblings wished they had not fought so much with the hospitalized child than the mothers perceived.

A comparison of the responses between fathers and well siblings are plotted (Figure 3). As was true for mothers and well siblings, this scattergram indicates there is little agreement between the fathers' and well siblings' responses. There also seems to be a trend for the well siblings to respond more extremely than the fathers as illustrated by the plotted points in the upper left quadrant of the 45° line.

Four items on which the fathers and well siblings particularly disagreed were: item 16; item 20; item 39; and item 47. Item 16 indicated that the well siblings thought their family liked each other or cared about each other more than the fathers perceived. On item 20, well siblings perceived that the mother and the hospitalized child got along better than the fathers perceived. On item 39, well siblings indicated that the father seemed more worried than usual; however, fathers perceived the well



■ 1,1 cell

☐ Extreme cell

Figure 3. Comparison of the responses between well siblings and fathers

siblings would not view them this way. On item 47, well siblings wished they had not fought so much with the hospitalized child than the fathers perceived.

In Figure 4, a comparison of the responses between mothers and fathers are plotted. This scattergram seems to indicate that even though there is disagreement between mothers' and fathers' responses, the mothers and fathers seem to agree more than do the mothers and the well siblings or the fathers and the well siblings.

Only one item, item 35, was found to be in the upper left quadrant of the 45° line indicating particular disagreement for the mothers and fathers. When parents were asked to guess how the well siblings would see them since the hospitalization, mothers indicated they would be viewed as more worried; however, fathers perceived the well siblings would not view the mothers this way.

Ancillary findings not related to the formal hypotheses will be presented in the following section.

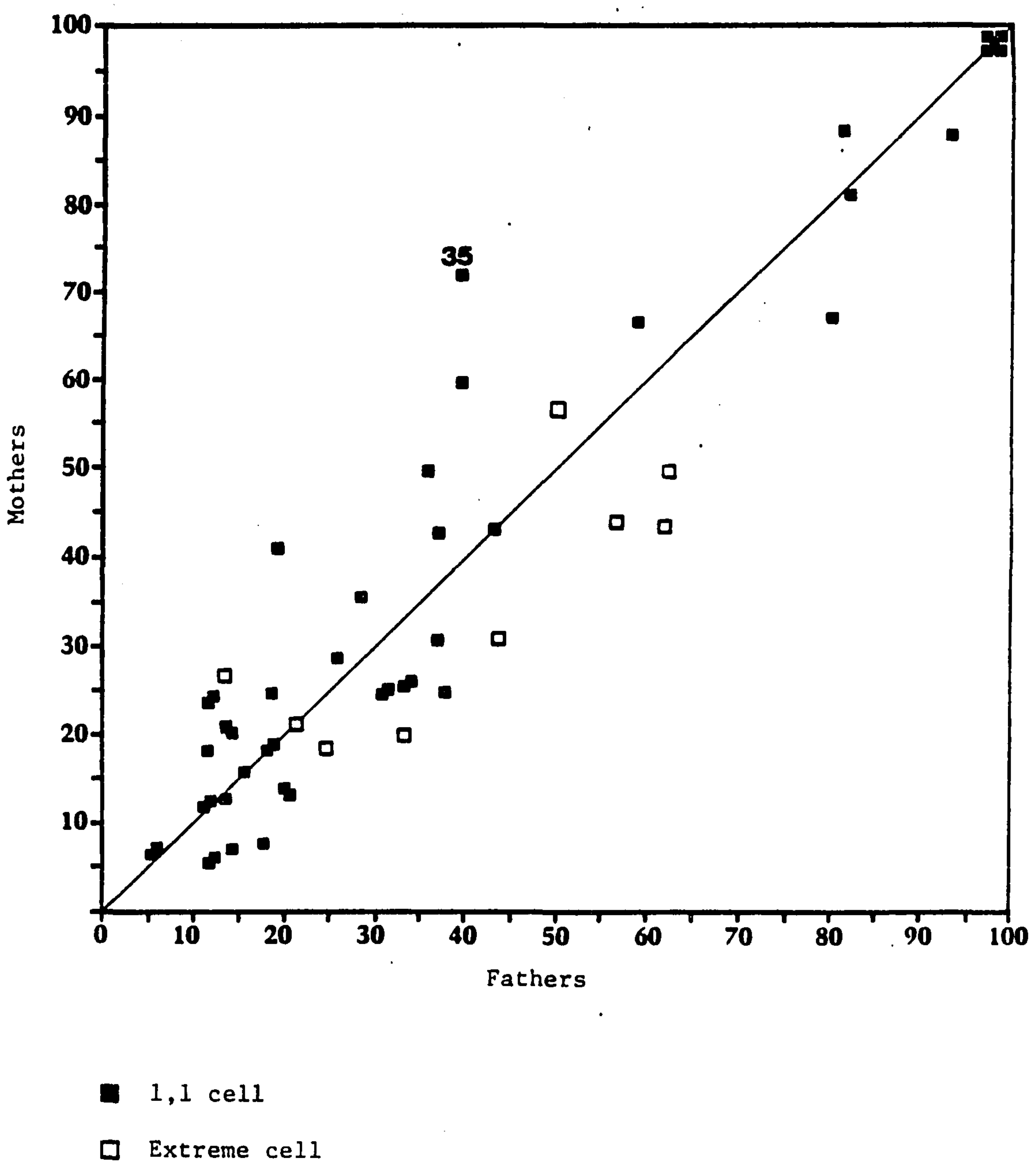


Figure 4. Comparison of the responses between mothers and fathers

SUMMARY, ANCILLARY FINDINGS AND DISCUSSION, AND RECOMMENDATIONS

Summary

The purpose of the present study was to investigate similarities and discrepancies of perceptions of well siblings and parents concerning an ill child's hospitalization. The following major family areas were identified for study: (a) family maintenance; (b) family relationships; (c) family communication; (d) health attitudes; and (e) perceptions of siblings, parents, and the hospitalized children.

Subjects of this study were 31 children, 13 boys and 18 girls, who had a sibling hospitalized in one of the hospitals in Athens, Georgia. The children selected for the study had to be between the ages of 6 to 15 years and have a hospitalized sibling who met the following research criteria: (1) age between 3 and 15 years; (2) length of hospitalization to be two or more days; and (3) no major impairments other than the one for which the child was hospitalized. Another criterion for sample selection was that no other family member had been hospitalized for more than two days during the year prior to the investigation.

Forty-two parents, 26 mothers and 16 fathers, of the well and hospitalized children were also subjects in this study. There were 16 mother-father pairs out of a possible 20 pairs with 6 mothers participating as single parents.

When a family was identified as meeting all the research criteria, an interviewer contacted the parents either in person or by telephone to explain the purpose of the study. If parents consented to having their family participate in the study, an appointment was arranged whereby the interviewer would go to the parents' home and administer a structured interview concerning perceptions about the hospitalization to the well sibling closest in age to the hospitalized child. The well sibling interview consisted of a 135 item questionnaire which was a combination of open-ended and close-ended questions. If a meeting in the parents' home was not convenient, a mutually agreed upon location was found where the interview could take place. An attempt was made to interview the well child on the second or third day of the ill child's hospitalization; however, this was not always feasible due to the difficulty in contacting families and the disruption of schedules occurring in some families.

After the well child completed the interview, parents were asked to fill out demographic data concerning their family. Once the parents completed this information, the interviewer requested the parents complete a 83 item paper pencil questionnaire concerning parents' perceptions about the hospitalization. The questionnaire was composed of 79 close-ended questions and 4 open-ended questions. If parents were unable to read, the interviewer read the questions aloud. A stamped, self-addressed envelope was provided so that parents who could read could complete the questionnaire and return it by mail. If after four days the parents had not returned the questionnaire, follow-up phone calls were made.

Upon completion of the data collection, 53 responses were coded for key punching for the well siblings, mothers, and fathers. The first computer print-out was for frequencies and percentages of the 53 close-ended questions on the parents' and well siblings' questionnaires, along with the demographic information from the parents' information form. The open-ended responses were also grouped at this time.

Two methods of computing were applied to the data. That is, with a 2 x 2 table the traditional chi-square test was utilized; with all other tables the diagonal totals (agreement) were taken against all other cells (disagreement) (Light, 1971). These chi-square procedures were applied to the 53 close-ended items on the well sibling and parent questionnaires. This enabled the researcher to examine the agreement and disagreement between the responses of the (1) well siblings and mothers, (2) well siblings and fathers, and (3) mothers and fathers.

The agreement between family members' perceptions of the hospitalization experience on the 53 items from the well siblings' and parents' questionnaires consisted of 42 significant chi-squares out of the 159 possible instances (agreement combinations). Mothers and well siblings agreed on 17 of 53 items, fathers and well siblings agreed on only 9 of 53 items, and mothers and fathers agreed on 16 of the 53 items. Thus, these findings indicate that parents are not always the best spokespersons concerning how family members perceive the hospitalization of the ill child.

In addition to the above computations, three scattergrams were drawn comparing the responses between the mothers and well siblings, fathers and well siblings, and mothers and fathers. Examination of the scattergrams comparing mothers' and fathers' responses and the fathers' and well siblings' responses showed little agreement between their responses, with a trend for the well siblings to indicate they have more concern than their parents perceive them to have. The scattergram comparing the responses of the mothers and fathers indicated that even though there was disagreement between mothers' and fathers' responses, the mothers and fathers seemed to agree more than did the mothers and well siblings or the fathers and well siblings.

To measure sibling concern about the hospitalization, nine open-ended questions which increased in specificity were designed to measure the saliency of how soon the well siblings would mention the hospitalized child or the hospitalization. On the first question, 43.33% of the sample made reference to the hospitalized child or the hospitalization, while 16.67% responded by the second question, and another 16.67% by the third question. Only 7 children in the sample responded by the fourth question or after. The well siblings' early reference to the hospitalized child or hospitalization was believed to indicate that the hospitalization of a sibling was in the forefront of their thoughts.

Ancillary Findings and Discussion

Literature comparing family members' perceptions of the ill child's hospitalization is practically nonexistent. Most studies have focused on the hospitalized child or the mother and only occasionally have fathers been part of the research data (Tew et al., 1974). While parents and the hospitalized children have been investigated, siblings have seldom been studied (Gogan, O'Malley, & Foster, 1977; Issner, 1972; Lavigne & Ryan, 1979; Spinetta, 1981a). Thus, it is difficult to make comparisons about agreement among family members' perceptions of hospitalization, as does the present study, with the existing literature which focuses on parents speaking for children or for themselves. Also, it must be noted that most of the literature utilizes adjectives to describe the results rather than statistical analyses, and studies are based on small numbers of subjects with subjective measurements and no suitable controls (Vance et al., 1980). All these factors contribute to making comparisons of studies difficult.

The discussion that follows will compare similarities and differences of the available literature with the present study to the extent possible given the above mentioned situations. The researcher also wants to make clear that the percentages utilize all respondents, while chi-squares utilize paired respondents. Thus, the results of the two procedures may not always appear to support each other.

Saliency

In the present sample, most well siblings (76.7%) made reference to the hospitalization of a brother or sister by the third question in a series of nine open ended questions designed to measure how soon the well siblings would mention the hospitalization. The interpretation of the saliency findings is contingent on one's view of the conscious vs. the unconscious.

If one ascribes to Freud's Psychoanalytic Personality Theory and the topographic viewpoint, then one believes that mental life represents conflict between the unconscious and the conscious parts of the mind. Every mental element is judged according to the accessibility to consciousness. To avoid pain or unpleasant experiences, certain thoughts would be repressed or barred from consciousness (Arlow, 1979; Brenner, 1973). Thus, if one takes Freud's viewpoint, the two well siblings who mentioned the hospitalization of a brother or sister last or close to the last of the series of questions would be the children who would be suffering the most or who were repressing their painful thoughts.

On the other hand, if one ascribes to Adler's Individual Psychology which rejects reductionism in favor of holism, the polarities of conscious and unconscious are nonexistent. From the Adlerian viewpoint, individuals are indivisible, social beings whose movement toward self-selected goals are consistent with their life style. Individuals create emotions to help them obtain their goals (Ansbacher & Ansbacher, 1964; Mosak, 1979). Thus, from Adler's perspective, well siblings who mentioned the hospitalization of a brother or sister soon in the series of questions would indicate more concern than those who mentioned the hospitalization later in the series of questions.

As a researcher, my position is that the well siblings' early reference to the hospitalization of a brother or sister indicated that the hospitalization was an area of concern for the well siblings and an issue that was in the forefront of their thoughts.

Family Maintenance

The family maintenance area encompassed household issues, caregiving issues, and family tasks. The well siblings, mothers, and fathers were each asked 10 questions concerning family maintenance when a child is hospitalized.

Household issues. The three household questions of concern during the ill child's hospitalization were: (1) parents' jobs; (2) talking about parents' money; and (3) transportation to and from the hospital.

On the area of household issues, there was no evidence of agreement between the well siblings and either parent. However, mothers and fathers agreed on two of three questions. The two questions which resulted in significant chi-squares concerned how much parents talked about money since the hospitalization and how much of a problem it was for parents to travel to and from the hospital. Thus, with household issues, there is evidence to support the fact that mothers and fathers can speak for each other better than for their well siblings.

Since the literature is lacking concerning agreement between the well siblings' and parents' perceptions, one might surmise that the well siblings in this study did not see their parents much. Some children stayed with relatives or neighbors while others stayed at home when their parents visited the hospitalized child. As a result, children had fewer opportunities to communicate with their parents. Also, depending on the family, a topic such as finances may or may not be discussed in front of the children. Parents, on the other hand, might have more opportunity to communicate as they travel to and from the hospital, and the resulting stresses may have been the primary topic of conversation. When comparing the findings in the present study to those which have been supported in the literature, there is a question of degree of agreement or disagreement.

During a child's fatal illness, several researchers described a tendency in fathers to withdraw into their jobs and use their work as an escape from the pain of the child's illness (Binger et al., 1969; Bozeman et al., 1955; Kartha & Ertel, 1976; Stehbens & Lascari, 1974). In the present study, 18.8% of the fathers reported that the child's hospitalization affected their job while 30.8% of the mothers and 35.5% of the well siblings reported parents' jobs were affected. While more mothers than fathers were affected by the illness in terms of their jobs, there is no evidence to contradict past research in this area. Yet, the researcher would speculate that the percentage of fathers being affected was so small that there would be a tendency to conclude that fathers did not withdraw into their work.

In the financial area, most family members agreed they discussed finances the same amount. One might speculate from these findings that if the discussion is the same, then the hospitalization is not a financial strain on the family. The present findings are in contrast to the literature. The financial strain of a child's hospitalization has often been described (Bozeman, 1955; Cairns, Clark, Black, & Lansky, 1979; Johnson et al., 1979; Kagen-Goodheart, 1977; Lansky et al., 1978; Rice, 1967). However, when considering the previous literature, it must be noted that the studies tended to focus on terminal patients where financial strain may be greater.

Traveling to and from the hospital can be a problem and leave parents tired (Bozeman et al., 1955; Easson, 1970; Kagen-Goodheart, 1977; Morse, 1974). In the present study, 38.7% of the children said traveling to and from the hospital was a large or medium problem while 50.0% of the mothers and 37.6% of the fathers reported traveling to and from the hospital as a large or medium problem.

Caregiving. The two caregiving questions concerned whether or not someone different was caring for the well sibling and where that care was being given since the hospitalization of the ill child. On these two caregiving questions, no evidence of agreement was found between the well siblings and the fathers or the mothers and fathers. Two significant chi-squares were reported for the mother-well sibling data. The agreement between the mothers and well siblings may indicate that mothers can speak for children in this area, but one would question asking fathers. It might be assumed that the close agreement found between the mothers and children was due to the fact that the mothers were most likely the primary caregivers of the children and made the primary caregiving arrangements. The lack of agreement between mothers and fathers and fathers and well siblings' may be due to the fathers not making child care arrangements and thus not being aware of the caregiving changes during the hospitalization of the ill child.

In the present study, 48.5% of the well siblings, 50.0% of the mothers, and 43.5% of the fathers answered that someone different was caring for the well child. These findings seem consistent with the literature that states when an ill child is hospitalized, families must often arrange for temporary care for the well siblings at home (Clapp, 1976; Freiberg, 1972; Johnson et al., 1979; Knafl, 1982).

In responding to the question whether the well children were being cared for in their own home or someone else's home, 72.0% of the mothers, 71.0% of the well siblings, and 81.3% of the fathers answered that their well child was being cared for in the family home. These findings seem to support Knafl's (1982) study in which 32.0% of 59 families who had a child hospitalized had some type of substitute care for the well siblings. Knafl reported a wide range of caregiving arrangements. Many families had someone outside the immediate household move in with the family for all or part of the hospitalization to care for the siblings, or someone outside the household made a minimal contribution such as feeding the children at meals or briefly watching them. Knafl also reported that in some families that had no outside substitute care the parents requested older children to care for younger siblings. Still other arrangements were to have well children spend the entire hospitalization in the home of a friend or relative or to shift children between substitute caregivers and home.

Family tasks. The five family task issues investigated were whether there was an increase in well siblings' chores or responsibilities, more work in meal preparation, more housework or yardwork, more work in caring for other well siblings, and more self-care responsibilities. Since many of these areas have not been specifically delineated in the literature, family tasks in general were discussed.

When establishing whether or not there was agreement among mother-sibling, father-sibling, and mother-father data, in only 3 out of 15 instances was significance obtained. It must be noted that all three items that reached significance were found between the mothers' and well siblings' responses. Mothers and well siblings agreed in the areas of whether the well siblings' responsibilities increased, if they had more housework or yardwork, and if they had more work in caring for themselves. The agreement between the mothers and well siblings on family tasks suggests that the mothers are better sources of information concerning the well siblings' family tasks than the fathers. Several possible explanations for the agreement among mothers and well siblings might be that the mother was the person assigning additional tasks to the well children and would know which responsibilities had increased. Another explanation may be that in this sample mothers might be perceived in the traditional role of running a home, and, therefore, it could be surmised that the mothers would be aware if the well siblings were completing household tasks and self-care responsibilities. On the other hand, fathers in these families may not be aware of who does specific family tasks.

In the present study, approximately 37.9% of the well siblings, 34.6% of the mothers, and 31.3% of the fathers reported that since the hospitalization the well siblings' chores or responsibilities increased. The well siblings indicated they had more work in meal preparation (41.9%), more housework or yardwork (48.4%), more work in caring for other well siblings (44%), and more work in caring for themselves (64.%). Both mothers and fathers did not report as great an increase in chores as did the children. Perhaps the well siblings perceived an increase in responsibilities because they were doing additional tasks previously done by their parents. The parents might have been oblivious to the well siblings' increase in responsibilities due to the parents' absence from the home and the stress of hospitalization.

The literature concurs that the distribution of family tasks is an area that affects families when a child is hospitalized (Knafl, 1982; Koocher & O'Malley, 1981). Knafl (1982) identified at least 21 of the 59 families she interviewed as having at least one well child assuming added tasks and responsibilities during the hospitalization. The type of additional responsibilities varied, but parents delegating care of a younger sibling to an older sibling and additional self-care responsibilities were often mentioned.

Family Relationships

The family relationship area included affection shown in the family, the parents' relationship with the well sibling, the parents' relationship with the hospitalized child, and the parents' relationship with each other. The well siblings, mothers, and fathers were each asked seven questions concerning family relationships when a child is hospitalized.

Affection. The two questions which examined affection concerned whether the family liked each other more, less, or the same and whether the other children in the family were getting along better, same, or worse. On these two questions, no evidence of agreement was found between fathers and well siblings. However, mothers and well siblings reached significant agreement on the question concerning the amount of affection shown in the family. This finding may be due to the mother being more active in the caretaking role and thus more attuned as to how the siblings view the hospitalization experience. The agreement between the mothers and well siblings may indicate that mothers can speak for children in this area, but one would question the fathers' views.

A significant chi-square was obtained for mothers' and fathers' agreement as to how the well siblings at home were getting along. The agreement in their perceptions may be due to the parents assuming the well sibling relationship was the same. The researcher believes the parents may be spending time visiting the hospitalized child, driving back and forth to the hospital, and being generally more concerned about the hospitalized child rather than focusing on the well siblings. Again, it seems wisest to let the siblings speak for themselves because the evidence supports the fact that the mothers and fathers can speak for each other better than for the well siblings.

In the present study, 64.5% of the well siblings perceived their family as liking each other or caring about each other more since the hospitalization, while 38.5% of the mothers and 12.5% of the fathers perceived the family liking each other or caring about each other more. A possible explanation for the finding is that the parents might always have shown concern and care about family members. Therefore, the hospitalization of a child does not increase his/her level of caring. On the other hand, siblings may have had little contact with hospitals and may have viewed the hospitalization experience as serious and thus increased their affection.

There seems to be some disagreement in the literature concerning the affection issue. Morse (1974), studying families involved in pediatric dialysis, found that families with close ties were brought closer together while divided families were torn farther apart by a medical crises. Litman (1971) concluded with similar findings showing that even though the hospitalization of one family member may cause disruption, an equal number of subjects said the illness either made family relationships more difficult or drew the family closer together. However, Lascari and Stehbens (1973) reported families becoming more united when facing a problem. Koocher and O'Malley (1981) interviewed 101 siblings of recovered cancer patients and reported that some siblings related positive aspects of cancer by experiencing enhanced feelings of closeness in the family and a growth in coping skills. Findings in the present study indicating that well siblings perceived more caring in the family seems to be supported by the literature. There seems to be some discrepancy in the literature, however, as to the fathers and mothers viewing the affection as the same in the family. It must be recognized, though, that most of the literature pertinent to affection shown in the family was from families where a child had a serious or terminal illness. In the present study, most children were not facing a life-threatening illness. Thus, perhaps even a greater increase in caring might have emerged if the child were facing a life-threatening illness.

In response to the questions asking if the brother(s) and sister(s) get along better, same, or worse since the hospitalization, most of the well siblings responded with same (52.0%), while 36.0% responded with better and 12.0% said worse. Most mothers (90.0%) and fathers (80.0%) reported that the well children at home get along the same. The literature that addresses how the well siblings view their relationships with the other well siblings at home is scarce. Harder and Bowditch (1982), however, investigated siblings of children with cystic fibrosis and found siblings reported that the illness had a positive force on the family, drew the family closer together, and that some siblings felt they were less self-centered since their brother or sister had become ill. An upsurge in feelings of intra-family closeness resulted in families immediately following a traumatic spinal cord injury to one of the child members, along with siblings taking on an interpreter role between the injured child and the parents (Cleveland, 1980). Findings of the present study appear consistent with the literature in that the well siblings may feel less self-centered and closer to the family, thus getting along with their well brothers or sisters at home the same or better. Again the reader must be aware that the literature reported tends to examine families where a child had more serious illnesses than children in the present study.

Parents' relationship with the well sibling. The two questions the well siblings and the parents were asked were how the well sibling got along with mother and how the well sibling got along with father since the hospitalization. There was no agreement between the mothers and well siblings, the fathers and well siblings, and the mothers and fathers. Since no agreement was found, the researcher concluded that each family member must speak for him/herself in this area.

The lack of agreement between family members might be due to the fact that parents may not have been spending as much time as usual with the well sibling, and thus it would be difficult to judge the status of the relationship. The literature tends to support the idea that when a well child has a brother or sister hospitalized, the well sibling feels isolated and excluded from the family (McAllister et al., 1973; Taylor, 1980). Another explanation might be that the hospitalization experience caused family members to act differently toward each other. Family members might have been more or less tolerant of each other during the hospitalization experience or the hospitalization may have made some family members more stressed resulting in irritability.

In the present study, most of the well siblings (64.5%), mothers (76.9%), and fathers (87.5%) said the well sibling and mother got along the same. Similarly, the well siblings (69.2%), mothers (81.0%), and fathers (87.5%) stated that the well sibling got along the same with father. These results seem to be somewhat inconsistent with the literature. However, the reader must be cautioned that many of the studies mentioned have been done with families where children had serious and/or terminal illnesses. Also, many of the studies did not report data directly on how the well sibling got along with his/her parent(s).

The present study indicates that most of the well siblings' relationships with their parents remained the same; however, this finding seems in conflict with the literature. Parents report well sibling jealousy, anger, feelings of abandonment, and guilt (Binger et al., 1969; Chodoff et al., 1964; Friedman et al., 1963; Heffron et al., 1973; Kaplan et al., 1973; Koocher & O'Malley, 1981). Reports of well siblings feeling isolated and excluded from the family were often noted (Everson, 1977; McAllister et al., 1973; Spinetta, 1978; Taylor, 1980). Burton (1975) found one-third of the sample he studied to have had problems with sibling behavior due to having a sick child in the family. If, in fact, siblings are reacting to the illness in this way, relationships among family members may be strained.

Sigal et al. (1973) felt their study confirmed that early childhood illness may result in parent-child relationship disturbances. In a retrospective study investigating families in which one child had been hospitalized before the age of 5 years, ill children saw their parents differently than the well siblings, and, in turn, the parents also perceived the previously ill child differently than the well sibling. While doing psychotherapeutic work with siblings of cancer patients, Sourkes (1980) mentioned that one of several recurring themes was relationships with parents. Lindsay and MacCarthy (1974) suggested that once a child becomes ill or hospitalized, parents' loss of confidence in parenting skills was sometimes generalized in feelings of inadequacy with other siblings. Based on the existing literature, one would expect the disruption of the hospital experience to cause the well siblings' relationships with their parents to be altered.

Lavigne and Ryan (1979) may give the reader some insight as to the reasons the family members perceived the well siblings' relationship with mother and/or father not to have changed. They concluded that the well siblings' adjustment problems seemed to differ in extent due to the particular illness. The researcher believes that since most of the illnesses in the present study were not life-threatening, siblings may have had fewer adjustment problems. It must also be remembered that the siblings were interviewed soon after the ill child was hospitalized, and thus their parental relationship may not have had much time to change. When interviewing siblings themselves about the impact of childhood cancer, Cairns, Clark, Smith, and Lansky (1979) concluded that the well siblings feared confronting family members with their negative feelings. Even though that study examined well siblings who had a brother or sister with cancer, the researcher believes it may be possible that the well siblings in this study may not have wanted to say their relationship with mother and father had changed because they knew their parents were under the strain of having a child hospitalized, or they did not want to say anything negative about family members.

Parents' relationship with the hospitalized child. The parents' relationships with the hospitalized child were measured by asking the well siblings, mothers, and fathers whether, since the hospitalization, mother and the hospitalized child and father and the hospitalized child got along better, same, or worse. On these two questions, there was no evidence of agreement between mothers and well siblings, fathers and well siblings, and mothers and fathers. The lack of agreement between family members may indicate that they were preoccupied with the hospitalization and were not communicating with each other. Some of the well siblings in the present study were not even staying in their own home and had little or no access to information about the hospitalized child. Also, some well siblings cared for in their own homes remarked to the interviewers that, since the hospitalization, they rarely, if ever, saw their parents. Thus, it seems imperative that each family member must speak for him/herself rather than reply on perceptions of family members.

Interesting findings in the present study revealed that the well sibling perceived mother and the hospitalized child getting along better (73.0%), while the mothers perceived they got along with the hospitalized child the same (84.6%), and fathers perceived mothers getting along with the hospitalized child the same (87.5%). A similar trend, though not as great, occurred when family members were asked how father and the hospitalized child were getting along. When looking at these responses, the well siblings indicated better (46.2%) or same (53.8%), while most of the parents responded the same (mothers 81.8% and fathers 87.5%).

When trying to compare the present study's findings to that of the existing literature, one notices the literature does suggest that the anxiety of the mother can be transmitted to the hospitalized child (Asen-Rudbarg Vardaro, 1978; Langford, 1961; Mechanic, 1964). Adams and Sarason (1963) concluded that anxiety may be meaningfully studied in the context of the family. If parents were worried or concerned, the well siblings would be able to recognize this cue. Thus, the researcher believes the parents, and in turn the well siblings, would be concerned about the hospitalized child. The well siblings may have assumed that because the parents, especially the mothers, were concerned about the hospitalized child, they would treat the child more kindly.

The literature documents that hospitalized school-age children respond to stressful situations in the hospital by crying, regressing in behavior, being irritable, and struggling against treatment or tests (Klinzing and Klinzing, 1977; Prugh et al., 1953; Vernon, Foley, & Schulman, 1967). The assumption could be made that most well siblings had some time in their life gone to a physician's office for an injection with a hypodermic needle or had some type of medical tests. Most likely the well siblings' reactions were similar to the inhospital behaviors mentioned above. The well siblings could remember how their mothers or fathers reacted. Another assumption might be that the parents reacted to the well siblings' stress with words of comfort and caring. The parents' reaction to an ill child in the home might be similar to the parents' reactions when the well siblings visit a physician. The parents may see their nursing and nurturing role as normal parenting responsibilities while the children may remember the extra attention and extra caring they received when they were ill. Thus, the well siblings, operating from the framework of how their parents treated them in the physician's office or when they were ill, perceived the parents getting along better with the hospitalized child. Cairns, Clark, Smith, and Lansky (1979) who interviewed siblings of children with cancer, found that the well siblings viewed their mother as more overprotective and overindulgent than the patients did. These findings may indicate that well siblings see their mother as very nurturing and caring since the hospitalization experience.

Another factor that may be important is that the well siblings may not be seeing much of their parents. Many well siblings were staying home or with caregivers when their parents visited at the hospital. Siblings could assume that all the time and attention their parents were spending with the hospitalized child meant that the parents cared for the hospitalized child and were, in turn, meeting his/her needs. Thus, parents would be getting along better with the hospitalized child. This type of rationale could be supported with Spinetta's (1981b) work showing that the patients' needs were met first, with mothers' and fathers' needs met nearly as well.

Siblings' needs, however, were met significantly less adequately than other family members.

Perceptions of the parents' relationship. One question the researcher asked well siblings, mothers, and fathers was how the mother and father got along since the hospitalization. On this question, there was no significant agreement between mothers and well siblings, fathers and well siblings, or mothers and fathers. From these findings, one can conclude that family members have different perceptions of the parents' relationship. Thus, it is important for each person to be questioned individually since there was no agreement as to family members' perceptions of the parents' relationship.

The data from the present study suggested that the well siblings viewed their parents as getting along better (36.0%) or the same (64.9%). Most mothers said they got along with their spouse the same (87.0%), while only a small number said better (4.3%) or worse (8.7%). Most fathers also believed they got along with their spouse the same (87.5%) or better (12.5%). The overall consensus of these findings was that the majority of family members perceived that the parents' relationship stayed the same.

The present study seems to be in conflict with several authors who have reported marital problems and a lack of support from a spouse in families when a child has a serious illness (Binger et al., 1969; Hamovitch, 1964; Heffron et al., 1973; Kaplan et al., 1973; Murstein, 1960; Tew et al., 1977). Literature that seems to be consistent with the finding of the study present that parents tend to get along has been cited by Koocher and O'Malley (1981), Lansky et al. (1978), and Lascari and Stehbens

(1973). There is very little literature available concerning how siblings perceive the parents' relationship; however, Lansky et al. (1978) mentioned that siblings may be affected by marital stress that occurs in families of hospitalized children. It must be noted, however, that, unlike the present study, all these literature findings refer to families where a child is seriously ill.

The present findings which suggest that most of the family members perceived the parents getting along the same or better seem consistent with the trend of findings throughout this study. Family members have consistently reported that, since the hospitalization, the parents' relationship with the hospitalized child and the well sibling(s) has been the same or better. These findings, in turn, seem consistent with the issue that the family as a whole unit likes each other and cares about each other more or the same. Thus, it appears the hospitalization of a child alters the status quo of the family very little, but when it does it seems to make family relationships better.

Family Communication

The three family communication questions investigated how much the family talked to each other since the hospitalization, whether the well sibling wished the family would talk about the hospitalized child more, same, or less and who told the well sibling about the hospitalized child's illness. Significant agreement was found for the mother-well sibling, father-well sibling, and mother-father data on the question of who told the well sibling about the hospitalized child's illness. Since family members agreed on this question, these findings may indicate that family members can speak for each other on this issue. Mothers and well siblings and mothers and fathers also agreed on the question concerning whether the well sibling wished his/her family would talk about the sick child being in the hospital more, same, or less. It seems from these findings that if a researcher is unable to obtain the necessary information from the well siblings, mothers may be a reliable source for family communication information.

Most family members believed that since the hospitalization the family talked to each other the same; however, almost a third of the well siblings (30.0%) reported the family talks more, and 16.7% reported the family talked less. These findings seem to indicate that parents do not feel the hospitalization has changed family communication, while almost half of the well siblings perceived it did. The literature does not discuss the amount of communication in families, but the literature does state that poor communication can make adjustment to the illness by the family difficult (Binger et al., 1969; Kaplan et al., 1973; Pearse, 1977). Further, a closed communication system in families of hospitalized children may contribute to emotional problems in the siblings (Koocher & O'Malley, 1981). It would seem, in the families of the present study, that the child's hospitalization did not disrupt communication patterns which, according to the literature stated above, may have made the adjustment to the illness easier.

When investigating whether well siblings wished their families would talk about the hospitalization more, less, or the same, most well siblings (66.7%), mothers (70.8%), and fathers (75.0%) responded with the word same. Only 16.7% of the siblings indicated they wished the family would talk about the hospitalized child more while another 16.7% indicated less. These results seem to suggest that most well siblings, mothers, and fathers perceived the well sibling as talking about the hospitalized child an adequate amount. These findings seem inconsistent with the literature which states well siblings often feel left out (Cairns, Clark, Smith, & Lansky, 1979; Clapp, 1976; Everson, 1977; Taylor, 1980); however, it is important to remember that the literature is based mostly on parent reports of well siblings of children with very serious illnesses. It seems that the families in the present study heeded the advice of Koocher and O'Malley (1981) and Spinetta (1981b) who advocated the necessity of communicating with siblings about the hospitalized child. The agreement between mothers and well siblings and fathers and mothers may be due to the mothers being the primary giver of information to the well siblings and possibly even the fathers about the hospitalized child.

There was significant agreement among family members concerning who told the well siblings about the hospitalized child's illness. Most well siblings chose the answer mother (45.2%) or both parents (16.1%) or others (25.8%). People classified as others were relatives or friends who were providing substitute care or other siblings in the family. Most mothers perceived the well siblings were told by the mothers (50.0%) or by both parents (30.9%), while most fathers selected the response mothers (37.5%) or both parents (43.8%). The close agreement on this question may be due to the fact that often parents were the ones who told the well siblings about the hospitalized child. Thus, since the interview occurred soon after the hospitalization, both the parents and the well siblings could recall who told them. The literature often does not make it clear as to who told the well siblings about the hospitalized child, but it advises that parents and even the parents and the physician inform the well sibling (Ablin et al., 1971; Binger et al., 1969; Heffron et al., 1973; Kaplan et al., 1973; Koocher & O'Malley, 1981).

Health Attitudes of the Well Siblings

The well siblings' health attitudes since the hospitalization were investigated by asking the well siblings, mothers, and fathers whether the well sibling had colds, infections, headaches, stomachaches, rashes, or other ailments and if the well sibling thought about getting sick and possibly going to the hospital more, same, or less. Looking at the data, one could conclude that most well siblings, mothers, and fathers reported the well siblings did not have the various illnesses; however, well siblings tended to report more health problems than the parents reported for the well siblings. Thus, as far as the physical health of the well sibling is concerned, there seems to be evidence to support that family members can speak for each other on this issue.

The literature states that siblings have to deal with great stress (Cairns, Clark, Smith, & Lansky, 1979) and may be frightened, anxious, or depressed (Freiberg, 1972; Groggin, Lansky, & Hassanein, 1976; Lansky & Gendel, 1978). Stress may manifest itself in common health problems such as headaches, depression, and abdominal pains in the well siblings (Binger et al., 1969). Gyulay (1975) reported that some siblings actually developed the same symptoms the ill child had or developed the same effects the ill child had resulting from his/her chemotherapy treatment. The parents in the present study may have been more aware of the well siblings' health because the hospitalization of the ill child had turned their attention to such physical health matters.

The question whether the well siblings thought about getting sick and possibly going to the hospital more, less, or the same produced very interesting findings. Mothers and fathers had significant agreement for this question, but well siblings and mothers and well siblings and fathers did not agree. Again it appears that parents can answer better for each other than they can for the well siblings. Most mothers (62.5%) and fathers (62.5%) perceived their well siblings would think about getting sick and possibly going to the hospital the same as always; however, most well siblings reported that they thought about it more (48.3%) while others reported they thought about it the same (31.0%). Even though most of the literature is based on well siblings of hospitalized children who have serious illnesses, the literature seems consistent with the present finding that it is common for the well siblings to think about and possibly fear catching the hospitalized child's illness (Binger, 1973; Binger et al., 1969; Feinberg, 1970; Johnson et al., 1979; Kagen-Goodheart, 1977; Kaplan et al., 1973; Koocher & O'Malley, 1981; McCollum, 1981; Morse, 1974; Patterson, 1973; Toch, 1974; Travis, 1978).

Perceptions of Family Members

The perceptions of family members' section is divided into the following three areas: perceptions of how well siblings perceive their parents;

perceptions of how the well siblings perceive themselves; and perceptions of the well siblings' and hospitalized child's relationship previous to the hospitalization. The well siblings, mothers, and fathers were each asked 26 questions concerning the perceptions of family members when a child is hospitalized.

Perceptions of how well siblings perceive their parents. This particular area focused on how family members thought the well siblings would perceive their parents. The questions concerned whether mother and father seemed busy, tired, worried, happier, grumpier, or the same and whether the well sibling was able to spend more, same, or less time together with mother and father since the hospitalization. Mothers and well siblings agreed on 4 of 10 questions. These questions concerned perceptions of mother seeming busy, tired, or worried and if father seemed worried. Fathers and well siblings agreed on only 1 of the 10 questions. This question concerned whether mother was more, less, or the same amount worried. These findings may indicate that the well siblings are more aware of their mothers' behavior than they are of their fathers' behavior. Mothers and fathers agreed on 4 of 10 questions. These questions concerned whether the parents perceived the well sibling would view mother and father as happier, grumpier, or the same and whether the well siblings had more, less, or the same amount of time to spend with mother and father. These findings seem to indicate that even though there is some agreement among family members' perceptions, it is not great enough to say family members can speak for each other. The trend continues, as discussed in previous findings, that there seems to be the least amount of agreement between fathers and well siblings.

The literature states that parents of children in pediatric units are often under stress and have emotional and adjustment problems (Cummings et al., 1966; McAllister et al., 1973; Turk, 1964). The literature also suggests that parents, especially mothers, may suffer extreme distress over their child's illness, hospitalization, and/or surgery (Belmont, 1970; Burling & Collipp, 1969; Duffy, 1972; Mechanic, 1964). Parents' reactions to serious illnesses are varied with parents exhibiting feelings of guilt, anxiety or worry, shock, alienation, or hostility (Binger et al., 1969; Chodoff et al., 1964; Johnson et al., 1979; Johnson & Miller, 1975; Knudson & Natterson, 1960). Since the literature says parents may be very anxious over the hospitalization, this might be translated to mean that parents would worry more and not be as happy as usual. Findings of the present study seem quite consistent with the literature for mothers but somewhat inconsistent for fathers. However, it must be emphasized that often research studies concentrated on mothers rather than on fathers about whom our knowledge base is limited (Koocher & O'Malley, 1981). Most well siblings, mothers, and fathers stated that both mother and father seem the same in terms of being happier or grumpier. For the questions concerning well siblings' perceptions of parental worry, most well siblings (70.0%) and mothers (72.0%) said mother seems more worried while most fathers (56.3%) indicated mother seems the same as far as worrying. On the question as to whether father seems more, same, or less worried, most well siblings (60.9%) indicated father seems more worried while most mothers (52.4%) and fathers (87.5%) indicated father seems the same as far as worrying since the hospitalization.

The literature states that hospitalization of a family member can disrupt family life (Litman, 1971). When a child is hospitalized, it has been established that parents must travel back and forth to visit the hospitalized child, and the traveling can leave the parents tired (Bozeman et al., 1955; Easson, 1970; Kagen-Goodheart, 1977; Morse, 1974). Besides traveling to and from the hospital, babysitters and substitute care for well siblings must be arranged (Johnson et al., 1979; Knafl, 1982). Thus, one could conclude that traveling to and from the hospital and making substitute care arrangements for well children while maintaining a household might make parents busier, more tired, and less able to spend time with the well sibling(s). The present findings seem to remain consistent with the above literature as to what we know about mothers. Since there is little data on fathers, it is difficult to make comparisons.

For the questions concerning well siblings' perceptions of how busy and tired mother seemed, most well siblings, mothers, and fathers reported mother seemed busier and more tired. On the other hand, most well siblings and mothers answered father seemed busier while most fathers answered they were not busier. As far as fathers seeming tired, most well siblings, mothers, and fathers reported father seemed the same. On the question concerning how much time the well sibling and mother were able to spend together since the hospitalization, well siblings, mothers, and fathers indicated well siblings were able to spend less time together with mother. However, on a similar question, except this time asking how much time father and the well sibling could spend together, most well siblings responded with either they spent the same amount (41.7%) or less time

(41.7%) together with father, while most mothers and fathers reported the same. The present findings seem to indicate that since the hospitalization, mothers are busier, more tired, more worried, and have less time to spend with the well siblings, while the fathers exhibited less change in these areas. This may be due to the mothers being the primary caretakers of both the children and the household and, therefore, being the ones who must balance visiting and caring for the hospitalized child with maintaining responsibilities to the well child(ren) at home and to running a household. Thus, the mothers' life has been more disrupted than the fathers since the hospitalization.

Perceptions of how well siblings perceive themselves. To determine how well siblings see themselves since the hospitalization, well siblings, mothers, and fathers were each asked 11 questions. The questions concerned whether the well sibling was worried, was afraid about the hospitalized child, was afraid s(he) might also get sick, was jealous of the attention the hospitalized child was receiving, was jealous about gifts the ill child was receiving, felt guilty, wished s(he) had not fought so much with the ill child, believed the hospitalization was someone's fault, was angry about the attention the hospitalized child received, missed the hospitalized child, and felt left out about what was happening to the hospitalized child.

In the area of how well siblings perceive themselves, there was no evidence of agreement between mothers and fathers. There was only one question that resulted in significant agreement for mothers and well siblings, and this concerned whether the well sibling wishes s(he) had not fought so much with the hospitalized child. The one question that was significant for the father-well sibling data concerned whether or not the well sibling was angry about the attention the hospitalized child received. The almost total lack of agreement by family members concerning how the well siblings perceived themselves since the hospitalization illustrates the great need for well siblings to speak for themselves.

The lack of agreement among family members might be due to the fact that parents, especially mothers, are busy caring for and visiting the hospitalized child and also are busy maintaining their households. Even though these parents may be communicating with the well sibling by giving him/her information about the hospitalized child, the parents do not seem to be understanding how the well sibling may really be perceiving the hospitalization. These surface level communications between parents and children may be due to parents being busy as previously mentioned and parents' preoccupation with the hospitalized child. Another factor may be that for the well siblings who were being cared for by substitute caregivers, some of the communications or even most of the communications with parents occurred over the phone. Thus, indepth conversations may not have taken place. The researcher noted, after completing the written parent questionnaire, several parents remarked that they had not really thought much about the well sibling. Several of these same parents mentioned they intended to take some time and talk with the well sibling about the hospitalization when their daily visit at the hospital was over.

Most well siblings (66.7%), mothers (80.8%), and fathers (81.3%) indicated that the well sibling was worried about the hospitalized child.

As to whether or not the well sibling was afraid about having a brother or sister hospitalized, about half the well siblings (54.8%) said no, while almost half said yes (45.2%). Most mothers (68.0%) and fathers (62.5%) said no. These findings seem consistent with the literature which says some well siblings may be anxious or worried (Cairns, Clark, Smith, & Lansky, 1979; Freiberg, 1972; Groggin et al., 1976; Grossman, 1975; Harder & Bowditch, 1982; Lansky & Gendel, 1978) or frightened for the hospitalized child (Freiberg, 1972) or fearful their hospitalized brother or sister would die (Heffron et al., 1973).

Concerning whether the well sibling was afraid s(he) might also get sick, 56.7% of the well siblings said no, while 43.3% said yes. Parents did not perceive their well siblings would feel this way. Most mothers (96.2%) and most fathers (81.3%) said no, indicating that the well child would not be afraid of becoming sick. The fact that some well siblings did indicate they were afraid of becoming ill is well-documented in the literature (Binger, 1973; Binger et al., 1969; Feinberg, 1970; Heffron et al., 1973; Hopkins, 1973; Johnson et al., 1979; Kaplan et al., 1973; Korsch & Barnett, 1961; McCollum, 1981; Morse, 1974; Patterson, 1973; Toch, 1974; Travis, 1978; Tropauer et al., 1970).

The questions of whether the well sibling feels jealous about the attention and presents the hospitalized child received and if the well sibling feels angry about the attention the hospitalized child received will be considered together. Most well siblings (73.3%), mothers (80.8%), and fathers (68.3%) indicated the well child did not feel jealous about the attention the hospitalized child received nor did most well siblings

(80.0%), mothers (84.6%), and fathers (81.3%) perceive the well sibling being jealous about the presents the ill child received. As far as being angry about the attention the hospitalized child received, most well siblings (96.8%), mothers (96.2%), and fathers (93.8%) indicated the well siblings were not angry. The present findings are difficult to compare to the literature because most of the literature does not indicate percentages of the sample that felt jealous or angry. In addition, the literature refers to children who had very serious illnesses. Koocher and O'Malley (1981) reported about 25% of their sample of well siblings felt jealous of the extra attention, a fact which is consistent with the present findings. The literature states that two of the presumed effects on siblings of children who are hospitalized or have chronic illnesses are jealousy and anger (Chodoff et al., 1964; Friedman et al., 1963; Gyulay, 1975; Heffron et al., 1973; Hopkins, 1973; Johnson et al., 1979; Kaplan et al., 1973; Korsch & Barnett, 1961; McCollum, 1981; Patterson, 1973; Toch, 1974; Travis, 1978; Tropauer et al., 1970). In light of the present findings, the researcher concluded the findings for the well siblings feeling jealous are consistent with the literature, but the findings for the well siblings' angry feelings over the attention the hospitalized child received are inconsistent.

Family members were asked whether the well sibling felt guilty, whether s(he) had a brother/sister hospitalized, and whether or not the well sibling wished s(he) had not fought so much with the hospitalized child. Most well siblings (76.7%), mothers (84.6%), and fathers (87.5%) responded that the well sibling did not feel guilty. On the question as to whether the well sibling wished s(he) had not fought so much with the hospitalized child, most well siblings (67.7%) answered yes; however, most mothers (76.0%) and fathers (62.5%) answered no. Those well siblings answering yes they wished they had not fought so much with the hospitalized child may have meant they felt guilty or sorry. When comparing the above findings to the literature, it must be remembered that once again the literature is based on seriously ill children, and the results are often described with adjectives rather than statistical findings. In looking at the literature as a whole, the present findings indicating some guilt feelings seem consistent with the literature (Chodoff et al., 1964; Friedman et al., 1963; Heffron et al., 1973; Hopkins, 1973; Johnson et al., 1979; Kaplan et al., 1973; Koocher & O'Malley, 1981; Korsch & Barnett, 1961; McCollum, 1981; Patterson, 1973; Toch, 1974; Travis, 1978; Tropauer et al., 1970). However, the present findings also seem consistent with the retrospective study done by Gogan, Koocher, Foster, and O'Malley (1977) where the siblings described very few feelings of guilt.

Most well siblings (76.7%) believed it was not someone's fault their brother or sister was hospitalized, while (23.3%) did believe it was someone's fault. Most mothers (92.3%) and fathers (93.8%) indicated the well siblings perceived it was not someone's fault their brother or sister was hospitalized. More well siblings indicated it was someone's fault than the parents indicated the well siblings would answer. The literature is scarce on this topic, but Koocher and O'Malley (1981) stated that well siblings who blamed others or themselves for the hospitalized child's illness lacked information about the illness. The researcher interpreted the present data to mean that in instances when well siblings indicated it was someone else's fault the child was hospitalized, it was because the children blamed the other participants in the accident (i.e., the playmate who pushed the child on the playground which resulted in the injury was labeled as the person whose fault it was that the brother or sister was hospitalized).

When investigating whether the well sibling missed the hospitalized child, most well siblings (87.1%), mothers (88.5%), and fathers (93.8%) indicated that yes the well siblings did miss the hospitalized child. These findings, though percentages are not always available, seem consistent with Freiberg (1972) where mothers reported siblings missed the hospitalized child. Groggin et al. (1976) and Lansky and Gendel (1978) reported siblings feel depressed when a child is hospitalized. The present researcher interpreted the above finding to mean some of the depression may be caused by the well sibling missing the hospitalized child. Caldwell (1982) advocated sibling visitation in the hospital as a means of reducing stress for both the hospitalized child and the well sibling. Thus, the present findings that the well siblings miss the hospitalized child seem to support the sparce literature available.

Concerning whether well siblings felt left out about what was happening to the hospitalized child, 41.9% of the well siblings believed yes they felt left out, while 58.1% reported not feeling left out. Most mothers (80.0%) and fathers (68.8%) perceived the well siblings as not feeling left out. The fact that the present findings indicated that some well siblings felt left out seems to be consistent with the literature that reports siblings feeling left out, isolated, or excluded from the family during the hospitalization (Cairns, Clark, Smith, & Lansky, 1979; Chodoff et al., 1964; Clapp, 1976; Everson, 1977; Friedman et al., 1963; Gogan, Koocher, Foster, & O'Malley, 1977; Groggin et al., 1976; Johnson et al., 1979; Kaplan et al., 1973; Lansky & Gendel, 1978; Taylor, 1980).

Perceptions of the well sibling's and hospitalized child's relationship previous to hospitalization. For this particular area, well siblings, mothers, and fathers were asked to rate the well siblings' and hospitalized child's relationship prior to hospitalization. Family members were asked whether the well sibling and hospitalized child did many things together, played or horsed around together, helped each other with problems, got along most of the time, and argued. Family members were to respond using never, sometimes, and often. Mothers and well siblings and fathers and well siblings did not significantly agree on any of the questions. Mothers and fathers had significant agreement on the question of whether the well sibling and the hospitalized child argued more, sometimes, or often. As has been the prevailing trend throughout the discussion of the findings, it seems that well siblings must speak for themselves rather than rely on parental perceptions.

Most of the well siblings (61.3%) reported they often did things with the hospitalized child, while most mothers said well siblings did things sometimes (53.8%) and most fathers reported often (62.5%). As far as the well siblings and the hospitalized child playing or horsing around together is concerned, most well siblings reported often (64.5%) while most mothers (57.7%) and fathers (56.3%) reported sometimes. Concerning whether the well siblings and the hospitalized child helped each other with problems, most well siblings (48.4%), mothers (73.1%), and fathers (75.0%) said this happened sometimes. When examining whether the well sibling and hospitalized child got along most of the time, most well siblings stated often (67.7%) while most mothers stated sometimes (61.5%) and most fathers stated often (56.3%). On the final question in this area concerning whether the well sibling and hospitalized child argued, most well siblings (61.3%), mothers (72.0%), and fathers (56.3%) responded with sometimes. The overall trend is that the well siblings tended to perceive their relationship with the hospitalized child as a little more caring than that of the parents' perceptions of the relationship between the well sibling and the hospitalized child.

The findings of the present study seem to be representative of sibling relationships. Siblings are reported to play with each other and seek each other's companionship (Smart & Smart, 1976; Sutton-Smith & Rosenberg, 1970). The literature also reports that siblings may be jealous and often quarrel with each other (Koch, 1960; Smart & Smart, 1977; Sutton-Smith & Rosenberg, 1970); however, siblings also report feeling close to each other (Bowerman & Dobash, 1974). Thus, the present findings seem to indicate that the well siblings in this study seem representative of the population.

Recommendations

Based upon the findings of this study, as well as the investigator's insights, several recommendations for future research are suggested. The first areas involved correcting certain limitations of the present study.

The first recommendation comes out of the sample size and type of illnesses. Not having access to a large medical complex serving children, it was necessary to utilize various nonterminal illnesses. It was also necessary to extend the collection of data over a period of 10 months and utilizing two hospitals. Thus, another researcher may wish to eliminate illness variation and an extended period of data collection by using a large medical complex.

The second recommendation coming out of the limitations of this study concerned interviewing. Well siblings were interviewed either in their home or a mutually agreed upon place set by the parents or the interviewer. Parents were contacted at home or at the hospital and asked to complete the Parent Questionnaire and return it by mail. For some parents who could not read, the interviewer would read the questions and mark the answers. These interviewing variations were beyond the reseacher's control. However, future researchers may wish to utilize hospital facilities for interviewing both parents and the well siblings.

The findings in the present investigation also suggest implications for further research. As noted in the discussion, the results of the present study are suggestive rather than conclusive and imply a need for additional investigation into the effect a child's hospitalization has on all family members. In view of the very limited number of well-designed studies dealing with how the well siblings actually perceive the hospitalization, further research is needed to provide understanding in this area. Replication studies are also necessary. More research utilizing different ages of children, different sample groups, different severity in illnesses of the hospitalized children, and other testing instruments would also give additional insights into how the well siblings perceive the hospitalization of a brother or sister.

The findings of this study give evidence that parents are not the best spokespersons for the well siblings and that the well siblings may respond more extremely to the hospitalization than their parents perceive. Therefore, the need for additional research on all family members, with a special emphasis on well siblings, is merited as a necessary and imperative part of preventative medicine and health care for children.

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APPENDIX A. QUESTIONNAIRE FOR WELL SIBLINGS

QUESTIONNAIRE FOR WELL SIBLING***

Warm Ups

1. How old are you? 1.____

2. Do you have your own room? 1. yes 2. no 2.____

a. If no, with whom do you share it? 3.____

I. General Questions

3. How are things going? 4.____

4. Are any new things happening? 5.____

a. If yes, what are they? 6.____

5. Have you been doing what you want lately? 7.____

a. If yes, what have you been doing? 8.____

6. Have things been different lately? 9.____

a. If yes, how have they been different? 10.____

7. What has upset you most recently? 11.____

8. What good things and bad things have been happening? 12._____

9. Has anything happened you wish hadn't? 13._____

   a. If yes, what happened? 14._____

10. Have there been any big changes in the family lately? 15._____

    a. If yes, what kind of changes? 16._____

11. How are things with your brother or sister? 17._____

II. Household and Caregiving Issues

A. Household Issues

12. How have mom's and dad's jobs been going lately? 18._____

13. Do mom and dad talk about money much? 1. yes 2. no 19._____

    a. Since _____ has been in the hospital, do mom and dad talk about money 20._____
       1. more
       2. about the same
       3. less

14. Do mom and dad talk about driving or using the car much? 21.______
1. yes 2. no

a. How much do you think traveling to and from the hospital is a problem for your parents? 22.______
1. it is a large problem
2. it is only a medium problem
3. it is no problem

B. Caregivers

15. Has anything changed about who is taking care of you since ______ is in the hospital? 1. yes 2. no 23.______

a. What ways has it changed? 24.______

b. Are you being cared for in 25.______
1. your own home
2. in someone else's home

16. If mom and/or dad go to the hospital for a visit, where do you go? 26.______
Code:
1. hospital
2. babysitter comes to home
3. stay by self at home
4. stay with other brothers and sisters at home
5. relative's home
6. neighbor's home
7. relative comes to our home
8. neighbor comes to our home
9. stay at home with one parent

C. Family Tasks

17. Tell me about your daily and weekly chores. 27.______

a. Since ______ has been in the hospital, now what are your daily and weekly chores? 28.______
Code:
1. increase
2. decrease

b. Who is doing _____'s chores now that s(he) is in the hospital? Code: 29.____
1. self
2. other siblings
3. mom
4. dad
5. no one
6. other__________

18. Since _____ has been in the hospital, how has your day changed? (Probe for interrupted family routine.) 30.____

19. Since _____ has been in the hospital, do you have more work with the following?

a. Meal preparation 1. yes 2. no 31.____

b. Housework or yardwork 1. yes 2. no 32.____

c. Caring for your brother and/or sister 1. yes 2. no 33.____

d. Caring for yourself 1. yes 2. no 34.____

20. Since _____ has been in the hospital, are you able to do 35.____
1. more things you like to do
2. things are just the same
3. less things you like to do

III. Family Relationships

A. Hospitalized Child and Well Sibling Relationship

21. Tell me about _____. 36.____

22. Before _________ went to the hospital, did you

a. do many things together? 1. never 2. sometimes 3. often 37.____

b. play or horse around together much? 1. never 2. sometimes 3. often 38.____

c. help each other with problems? 1. never 2. sometimes 3. often 39.____

d. get along most of the time? 1. never 2. sometimes 3. often 40.____

e. argue much? 1. never 2. sometimes 3. often 41.____

23. Since _____ has been in the hospital, how have your feelings changed toward him/her? Do you feel 42._____
1. more close
2. the same
3. less close

B. Affection in the Entire Family

24. How does your family show they like each other? 43._____

25. Since _____ went to the hospital, do you think your family likes each other or cares about each other 44._____
1. more
2. same
3. less

26. Since _____ went to the hospital, do you and your other brothers and/or sisters get along 45._____
1. better
2. same
3. worse

27. Does mom have a favorite in the family? 1. yes 2. no 46._____

a. If yes, who is it? 47._____
1. self
2. hospitalized child
3. other sibling
4. we all are

b. Has it always been that way? 1. yes 2. no 48._____

c. If no, how has it changed? 49._____

28. Does dad have a favorite in the family? 1. yes 2. no 50._____

a. If yes, who is it? 51._____
1. self
2. hospitalized child
3. other sibling
4. we all are

b. Has it always been that way? 1. yes 2. no 52._____

c. If no, how has it changed? 53._____

C. Parent's Relationship with the Well Sibling

29. Since _____ is in the hospital, how do you get along with mom? 54._____
Code: 1. we get along better
2. we get along the same
3. we get along worse

30. Since _____ is in the hospital, how do you get along with dad? 55._____
Code: 1. we get along better
2. we get along the same
3. we get along worse

D. Parent's Relationship with Hospitalized Child

31. How do you think mom gets along with _____ since s(he) has been in the hospital? 56._____
Code: 1. they get along better
2. they get along the same
3. they get along worse

32. How do you think dad gets along with _____ since s(he) has been in the hospital? 57._____
Code: 1. they get along better
2. they get along the same
3. they get along worse

E. Parents' Relationship

33. How do mom and dad get along? 58._____

a. Has it changed since the hospitalization? 59._____
Code: 1. better than usual
2. just the same
3. worse than usual

IV. Family Communication

34. What kinds of things do you and mom talk about? 60._____

a. When do you talk with each other the most? 61._____

b. Has it changed? 1. yes 2. no 62._____

c. If yes, what ways has it changed? 63._____

35. What kinds of things do you and dad talk about? 64._____

a. When do you talk with each other the most? 65._____

b. Has it changed? 1. yes 2. no 66._____

c. If yes, what ways has it changed? 67._____

36. Does your family talk about _____ being in the hospital? 68._____
1. yes 2. no

a. What do you think about that? 69._____

37. Since _____ has been in the hospital, would you say your family talks to each other 70._____
1. more
2. about the same
3. less

38. Do you wish your family would talk about _____ being in the hospital 71._____
1. more
2. about the same
3. less

V. Health Attitudes

39. How have you been feeling lately? 72.____

a. Since ________ went to the hospital, have you had any 73.____

(1) colds 1. Yes 2. No
(2) infections 1. Yes 2. No
(3) headaches 1. Yes 2. No
(4) stomachaches 1. Yes 2. No
(5) rashes 1. Yes 2. No
(6) other ________

40. Do you think about getting sick and possibly going to the hospital? 74.____

1. more
2. about the same
3. less

VI. Well Child's Perception of Parent

41. Describe how mom has been acting lately. 75.____

76.____

a. Check for things such as mom seems

(1) 1. More busy 2. About the same 3. Less busy
(2) 1. More tired 2. About the same 3. Less tired
(3) 1. Happier 2. About the same 3. Grumpier
(4) 1. More worried 2. About the same 3. Less worried

b. Check to see if there is a difference in mom's behavior. 77.____

c. Since the hospitalization, do you and mom spend 78.____

1. more time together
2. same amount of time together
3. less time together

42. Describe how dad has been acting lately. 79._____

a. Check for things such as dad seems 80._____

(1)	1. More busy	2. About the same	3. Less busy
(2)	1. More tired	2. About the same	3. Less tired
(3)	1. Happier	2. About the same	3. Grumpier
(4)	1. More worried	2. About the same	3. Less worried

b. Check to see if there is a difference in dad's behavior. 81._____

c. Since the hospitalization, do you and dad get to spend 82._____

1. more time together
2. same amount of time together
3. less time together

VII. Knowledge of Illness

43. What is wrong with _____? 83._____

44. Can you tell me about the illness? 84._____

Code:
1. extremely good understanding
2. good understanding
3. fair understanding
4. poor understanding
5. no understanding

45. Who told you about your brother or sister's illness? 85._____

Code:
1. mom
2. dad
3. both parents
4. medical staff
5. other__________

46. Who do you talk to about _____ being in the hospital? 86._____

Code:
1. mom
2. dad
3. teacher
4. friend
5. relative
6. another sibling
7. other__________

47. Are there any questions you have about _____ being in the hospital that have not been answered? 1. yes 2. no — 87._____

a. If yes, what are they? — 88._____

VIII. Well Child's Perception of Self

48. Do you worry about anything? 1. yes 2. no — 89._____

a. What kinds of things do you worry about? — 90._____

b. Are you worried about _____ being in the hospital? 1. yes 2. no — 91._____

49. Are you afraid of anything? 1. yes 2. no — 92._____

a. What kinds of things are you afraid of? — 93._____

b. Are you afraid about having _____ in the hospital? 1. yes 2. no — 94._____

c. Are you afraid you might get sick too? 1. yes 2. no — 95._____

50. Do you ever get jealous? 1. yes 2. no — 96._____

a. What kinds of things make you jealous? — 97._____

b. What do you think about all the attention your hospitalized brother or sister is getting? — 98._____

c. Are you ever jealous about all the attention the sick child gets? 1. yes 2. no 99._____

d. Are you ever kind of jealous about the presents he/she receives because they are in the hospital? 1. yes 2. no 100._____

51. Do you ever feel guilty about anything? 1. yes 2. no 101._____

a. What kinds of things make you feel guilty? 102._____

b. Do you feel guilty that _____ is in the hospital? 103._____
1. yes 2. no

c. Do you ever wish you hadn't fought so much with _____? 104._____
1. yes 2. no

d. If yes, how come? 105._____

e. Is it anyone's fault that _____ is sick? 1. yes 2. no 106._____

f. If yes, who? 107._____
1. hospitalized child
2. well child
3. other__________
4. no one

52. Do you ever feel angry? 1. yes 2. no 108._____

a. What kinds of things make you angry? 109._____

b. What kinds of things does _____ do that make you angry? 110._____

c. What do you think of the attention _____ is getting? 111._____

53. Do you ever feel lonesome? 1. yes 2. no 112.____

a. What kinds of things make you feel lonesome? 113.____

b. When do you feel lonesome most of all? 114.____

c. What is it like with ____ being gone? (Do they miss the hospitalized child?) 115.____

54. Do you ever feel left out about what is happening in the family? 1. yes 2. no 116.____

a. What kinds of things make you feel left out? 117.____

b. Do you feel left out about what is happening to ____ while s(he) is in the hospital? 1. yes 2. no 118.____

55. What is the best thing about having ____ in the hospital? 119.____

56. What is the worst thing about having _____ in the hospital? 120._____

57. Have you changed in any way since _____ went to the hospital? 121._____
1. yes 2. no

a. If yes, in what way? 122._____

IX. Well Child's Perception of Hospitalized Child

58. How do you think ____________________ feels about being in the hospital? 123._____

a. Check for feelings such as 124._____
1. upset
2. worry
3. fear
4. loneliness
5. guilt
6. jealousy
7. anger
8. shyness

X. Added Services (Optional Section)

59. Can you think of anything the hospital does not have that would be helpful to you, your brother or sister, or to your parents? 125._____

APPENDIX B. QUESTIONNAIRE FOR PARENTS

QUESTIONNAIRE FOR PARENTS*

I. Basic Household and Caregiving Issues

A. Parent Employment Issues

1. Has your child's hospitalization affected your job in any way? 1._____
   1. yes 2. no

   a. If yes, please explain. 2._____

B. Financial Issues

2. Since your child has been in the hospital, do you think and talk money 3._____
   1. more
   2. about the same
   3. less

C. Transportation

3. How much do you think traveling to and from the hospital is a problem for you? 4._____
   1. it is a large problem
   2. it is only a medium problem
   3. it is no problem

D. Caregivers

4. Before the hospitalization, who had the prime responsibility for the care of your well child? 5._____
   1. mom
   2. dad
   3. both parents
   4. other

5. Since the hospitalization, is someone different caring for your well child? 1. yes 2. no 6._____

   a. If yes, who? 7._____
   1. relative
   2. neighbor
   3. friend
   4. other__________

6. Since the hospitalization, where is your well child(ren) being cared for? 8._____
   1. in your own home
   2. in someone else's home

7. Since your child has been in the hospital, does anyone come into your home to help your family do any of the following?

a. Babysitting 1. yes 2. no 9._____
b. Transporting you or family members to daily activities 1. yes 2. no 10._____
c. Meal preparation 1. yes 2. no 11._____
d. Housecleaning 1. yes 2. no 12._____
e. Shopping 1. yes 2. no 13._____
f. Other 1. yes 2. no 14._____
g. If you have answered yes to any of the above, who are these caregivers? 15._____
1. relative
2. neighbor
3. friends
4. other__________

E. Family Tasks

8. Since the hospitalization, has ________'s daily routine been interrupted? 1. yes 2. no 16._____

a. If yes, in what ways? 17._____

9. Since the hospitalization, has ________'s chores or responsibilities increased? 1. yes 2. no 18._____

10. Since the hospitalization of your child, have you delegated more work to ________ in the following areas? 19._____

a. Meal preparation 1. yes 2. no 20._____
b. Housework or yardwork 1. yes 2. no 21._____
c. Care of other well siblings in the home (babysitting younger siblings) 1. yes 2. no 22._____
d. Caring for his/herself 1. yes 2. no 23._____
e. Laundry 1. yes 2. no 24._____
f. Shopping 1. yes 2. no 25._____
g. Other__________ 1. yes 2. no 26._____

II. Family Relationships

A. Rate the Hospitalized Child and Well Sibling(s) Relationships

On a scale of 1 to 3, rate the relationships between the hospitalized child and ________. Please make your ratings based on the relationships prior to hospitalization. The rating of 1 means it never occurs, a rating of 2 means is sometimes occurs, and a rating of 3 means it happens often.

Never	Sometimes	Often
1	2	3

11. Do many things together ________ 27._____

12. Play or horse around together much ________ 28._____

13. Help each other with problems ________ 29._____

14. Get along most of the time ________ 30._____

15. Argue ________ 31._____

B. Affection in the Entire Family

16. Since the hospitalization, do you think your family likes each other or cares about each other — 32.____
    1. more
    2. same
    3. less

17. Since the hospitalization, do your other children get along — 33.____
    1. better
    2. same
    3. worse

C. Parent's Relationship with the Well Sibling

18. Since the hospitalization, mom and ________ get along — 34.____
    1. better
    2. the same
    3. worse

19. Since the hospitalization, dad and ________ get along — 35.____
    1. better
    2. the same
    3. worse

D. Parent's Relationship with Hospitalized Child

20. Since the hospitalization, mom and the hospitalized child get along — 36.____
    1. better
    2. the same
    3. worse

21. Since the hospitalization, dad and the hospitalized child get along — 37.____
    1. better
    2. the same
    3. worse

E. Parents' Relationship

22. Since the hospitalization, do you and your spouse get along — 38.____
    1. better
    2. the same
    3. worse

III. Family Communication

23. Since your child has been in the hospital, would you say your family talks to each other — 39.____
    1. more
    2. about the same
    3. less

24. Do you think ________ wishes his/her family would talk about the sick child being in the hospital — 40.____
    1. more
    2. about the same
    3. less

IV. Health Attitudes

25. Since the hospitalization, has ________ had any of these?
a. Colds 1. yes 2. no 41._____
b. Infections 1. yes 2. no 42._____
c. Headaches 1. yes 2. no 43._____
d. Stomachaches 1. yes 2. no 44._____
e. Rashes 1. yes 2. no 45._____
f. Other__________ 46._____

26. Do you think ________ thinks about getting sick and possibly going to the hospital? 47._____
1. more
2. about the same
3. less

V. Well Child's Perception of Parent

Please answer the following questions in relation to how you would guess ________ would see you since the hospitalization.

Since ________ went to the hospital . . .

27. Is mom busier? 1. yes 2. no 48._____

28. Mom seems to be 49._____
1. more tired
2. about the same
3. less tired

29. Mom seems 50._____
1. happier
2. about the same
3. grumpier

30. Mom seems 51._____
1. more worried
2. about the same
3. less worried

31. Is dad busier? 1. yes 2. no 52._____

32. Dad seems to be 53._____
1. more tired
2. about the same
3. less tired

33. Dad seems 54._____
1. happier
2. about the same
3. grumpier

34. Dad seems 55._____
1. more worried than usual
2. about the same
3. less worried

35. Mom and dad argue 56._____
1. more
2. about the same
3. less

VI. Knowledge of Illness

36. How would you rate your understanding of your child's illness? 57._____
    1. extremely good understanding
    2. good understanding
    3. fair understanding
    4. poor understanding
    5. no understanding

37. Who told ________ about the hospitalized child's illness? 58._____
    1. mom
    2. dad
    3. both parents
    4. medical staff
    5. other__________ (please specify)

38. How much information was given to ________ about the hospitalized child's illness? 59._____
    1. full information
    2. part information
    3. no information

    a. What was your reasoning behind the amount of information given? 60._____

    b. Were all children given the same amount of information? 61._____
    1. yes 2. no

    c. If no, what is your reasoning? 62._____

VII. Well Child's Perception of Self

39. ________ is worried about the hospitalized child. 1. yes 2. no 63._____

40. ________ is afraid about having his brother/sister hospitalized. 1. yes 2. no 64._____

41. ________ is afraid s(he) might also get sick. 1. yes 2. no 65._____

42. ________ is jealous about all the attention the hospitalized child is getting. 1. yes 2. no 66._____

43. ________ is jealous about the presents his ill brother or sister receives. 1. yes 2. no 67._____

44. ________ feels guilty that s(he) has a brother or sister in the hospital. 1. yes 2. no 68.________

45. ________ wishes s(he) hadn't fought so much with the hospitalized child. 1. yes 2. no 69._____

46. ________ believes it is someone's fault that his brother or sister is hospitalized. 1. yes 2. no 70.____

47. ________ is angry about the attention the hospitalized child receives. 1. yes 2. no 71.____

48. ________ misses the hospitalized child. 1. yes 2. no 72.____

49. ________ feels left out about what is happening to his/her hospitalized brother or sister. 1. yes 2. no 73.____

50. Since the hospitalization, ________ and mom are able to 74.____
    1. spend more time together
    2. spend about the same amount of time together
    3. spend less time together

51. Since the hospitalization, ________ and dad are able to 75.____
    1. spend more time together
    2. spend about the same amount of time together
    3. spend less time together

VIII. Family Stress

A. Rating the Family Stress

On a scale of 1 to 5, rate your family's stress that has been caused by your child's hospitalization. A rating of 1 means there is low family stress, a rating of 3 means there is moderate family stress, and a rating of 5 means high family stress.

Low Stress	Little Stress	Moderate Stress	Some Stress	High Stress
1	2	3	4	5

52. Total family stress. 76.____

53. Your own personal stress. 77.____

54. Your spouse's stress. 78.____

55. The hospitalized child's stress. 79.____

56. ________'s stress 80.____

IX. Hospital Services (Optional)

57. Would the hospitalized child be helped if his/her brother(s) and/or sister(s) could visit? 1. yes 2. no 81.____

58. Would ________ be helped if s(he) could visit the hospitalized child? 1. yes 2. no 82.____

59. What do you think would have made this hospitalization experience easier on the well child(ren) in the family? 83.____

APPENDIX C. PARENTS INFORMED CONSENT

INFORMED CONSENT

The University of Georgia
College of Home Economics
Dawson Hall
Athens, Georgia 30602
(404) 542-2551

DEPARTMENT OF CHILD & FAMILY DEVELOPMENT

Dear Parent(s):

I am asking permission for you and your child to participate in a research project. This project involves obtaining your permission for a 40-minute interview with one of your well children and for you to complete a 15-minute questionnaire. The hospitalized child will not be interviewed. The study is only concerned with your reactions and the reactions of your well child to the hospitalization of his/her brother or sister. The areas in which you and your well child will be asked to respond have to do with changes that may or may not have occurred with family life since the hospitalization, such as caregiving and household issues, family relations, knowledge of illness, and health attitudes. Hopefully, the results of this study will help health care professionals develop programs to assist families when a child is hospitalized.

Your well child will be asked to give permission to tape record the interview so the researcher can check the accuracy of the data collected. You will be asked to complete a questionnaire and return it to me in a prepaid envelope. All information from the interviews and questionnaires will be coded, summarized, and placed in the computer. As soon as this process is completed, all questionnaires and tapes will be destroyed. Thus, there will be no possible way to identify you or your child by name. I assure you all information will be kept confidential. There are no right or wrong responses, and both you and your child will be free to not answer any questions you choose.

If you have any questions about either your own or your child's participation in this research project, please feel free to call me at the numbers listed below. A summary report of this project will be available to all families once the study is completed.

Please indicate whether you are willing to permit you and your child to participate in this study by signing the form below. Thank you for considering this research request during a time when you are confronted with many difficulties.

Sincerely,

Charlotte Wallinga

Charlotte Wallinga
404 549-5465 (home)
404 542-2551 ext 300 (work)

I am willing to participate in this study.	yes	no
You may interview my well child at home.	yes	no

Signed______________________________ Date______________

APPENDIX D. INFORMED CONSENT FOR 14 AND 15 YEAR OLDS

INFORMED CONSENT FOR 14 AND 15 YEAR OLDS

The University of Georgia
College of Home Economics
Dawson Hall
Athens, Georgia 30602
(404) 542-2551

· DEPARTMENT OF CHILD & FAMILY DEVELOPMENT

Dear

I am asking your permission to participate in a research project. This project involves having you complete a 40-minute interview with a researcher and also having your parent(s) complete a questionnaire they will mail back to me. The study is only concerned with your reactions and your parent(s) reactions to the hospitalization of a brother or sister. The areas in which you and your parent(s) will be asked to respond have to do with changes that may or may not have occurred with family life since the hospitalization, such as caregiving and household issues, family relations, knowledge of illness, and health attitudes.

You also will be asked permission to tape record the interview so the researcher can check the accuracy of the data collected. All information from the interviews will be coded, summarized, and placed in the computer. As soon as this process is completed, all tapes will be destroyed. Thus, there will be no possible way to identify you by name. I assure you all responses will be kept confidential. There are no right or wrong responses, and you are free to not answer any questions you choose.

If you have any questions about your participation in this research project, please feel free to call me at the numbers listed below. A summary report of this project will be available to all families once the study is completed.

Please indicate whether you are willing to participate in this study by signing the form below. Thank you for your cooperation.

Sincerely,

Charlotte Wallinga

Charlotte Wallinga
404 549-5465 (home)
404 542-2551 ext 300 (home)

I am willing to participate in this study. yes no

Signed________________________________ Date__________________

APPENDIX E. PARENT INFORMATION FORM

PARENT INFORMATION*

1. Number of miles from hospital 1.____

   1. under 10 miles
   2. 11 to 20
   3. 21 to 30
   4. 31 to 40
   5. 41 to 50
   6. 51 to 100
   7. over 100

2. Length of time in community 2.____

   1. under 6 months
   2. 6 months to under 1 year
   3. 1 year to under 2 years
   4. 2 years to under 3 years
   5. 3 years to under 4 years
   6. 4 years to under 5 years
   7. 5 years or over

3. Number of operating motor vehicles you own (cars, trucks, and motorcycles) 3.____

   1. zero
   2. one
   3. two
   4. three
   5. four or more

4. Is the area in which you live primarily 4.____

   1. rural
   2. suburban
   3. urban

5. Your marital status 5.____

   1. single parent
   2. married
   3. remarried

6. If married, how many years have you been married? 6.____

   1. under 1 year
   2. 1 year to under 3 years
   3. 3 years to under 5 years
   4. 5 years to under 10 years
   5. 10 years or more

7. If a single parent, how many years have you been a single parent? 7._____

    1. under 1 year
    2. 1 year to under 3 years
    3. 3 years to under 5 years
    4. 5 years to under 10 years
    5. 10 years or more

8. Your age 8._____

    1. 26-30 years
    2. 31-35 years
    3. 36-40 years
    4. 41-45 years
    5. 46-50 years
    6. 51-55 years
    7. 56-60 years
    8. 61-65 years
    9. 66 or over

9. Your education (check the highest level obtained) 9._____

    1. some grade school
    2. completed grade school
    3. some high school
    4. completed high school
    5. some college
    6. completed college
    7. advanced degree after completing four years of college

10. Your employment status 10._____

    1. full-time homemaker
    2. employed full time outside the home
    3. employed part time outside the home
    4. unemployed and looking for work
    5. retired
    6. full-time student
    7. other (please specify)______________________________

11. Your occupation (please describe as fully as you wish) 11._____

____

If you are presently married, please fill in the following information about your spouse.

12. Spouse's age 12._____

    1. 26-30
    2. 31-35
    3. 36-40
    4. 41-45
    5. 46-50
    6. 51-55
    7. 56-60
    8. 61-65
    9. 66 or over

13. Spouse's education 13._____

1. some grade school
2. completed grade school
3. some high school
4. completed high school
5. some college
6. completed college
7. advanced degree after completing four years of college

14. Spouse's employment status 14._____

1. full-time homemaker
2. employed full time outside the home
3. employed part time outside the home
4. unemployed and looking for work
5. retired
6. full-time student
7. other (please specify)______________________________

15. Your spouse's occupation (please describe as fully as you wish) 15._____

____

16. Who lives with the hospitalized child at the present time?

Name Relationship (mother, father, sibling, etc.) Age

1.____

2.____

3.____

4.____

5.____

6.____

7.____

8.____

APPENDIX F. COVER LETTER EXPLAINING PARENT QUESTIONNAIRE

COVER LETTER EXPLAINING PARENT QUESTIONNAIRE

The University of Georgia
College of Home Economics
Dawson Hall
Athens, Georgia 30602
(404) 542-2551

DEPARTMENT OF CHILD & FAMILY DEVELOPMENT

Dear Parent(s):

I am interested in the effects of hospitalization of a child on the family, with a special emphasis on the well brother or sister at home. I would like to learn more about this area and need your help.

Please complete the attached questionnaire and return it to me in the prepaid envelope as soon as possible. It should only take 15 to 20 minutes. There are no right or wrong answers. I simply am trying to gather information as to what effect, if any, the hospitalization has on family members. Any questions you do not choose to answer may be left blank. If there are two parents in the home I would appreciate it if both of you would complete individual questionnaires.

In that this dissertation study is part of my Ph.D. requirements at Iowa State University, it will be available to others. Thus, no names will be used and all responses will be confidential. Only the location of the hospital will be divulged. I have asked for some information about yourself but I assure you that you will not be identified by your answers. Instead of names on the questionnaires, numbers have been used. These numbers will help me keep the families straight and allow the data to be coded.

If you have any questions about your participation in this research project, please feel free to call me at the numbers listed below. Thank you for the time and effort you are putting into this project. A summary report of the project will be available when the study is completed.

Thanks again for your help and cooperation. I will be looking forward to your response.

Sincerely,

Charlotte Wallinga

Charlotte Wallinga
404 549-5465 (home)
404 542-2551 ext 300 (work)

APPENDIX G. DEMOGRAPHIC DATA

Demographic Data

1. Age of Well Siblings (N=31)

	N	%
1. 6 years	1	3.2
2. 7 years	1	3.2
3. 8 years	2	6.5
4. 9 years	4	12.9
5. 10 years	4	12.9
6. 11 years	3	9.7
7. 12 years	5	16.1
8. 13 years	6	19.4
9. 14 years	2	6.5
10. 15 years	3	9.7

2. Sex of Well Siblings (N=31)

	N	%
1. male	13	41.9
2. female	18	58.1

3. Ethnic Group (N=31)

	N	%
1. American Indian	0	0.0
2. Asian or Pacific Islander	0	0.0
3. Black	9	29.0
4. Hispanic	0	0.0
5. White	22	70.9

4. Age of Hospitalized Child (N=31)

	N	%
1. 3 years	2	6.5
2. 4 years	5	16.1
3. 5 years	5	16.1
4. 6 years	0	0.0
5. 7 years	2	6.5
6. 8 years	4	12.9
7. 9 years	3	9.7
8. 10 years	0	0.0
9. 11 years	1	3.2
10. 12 years	3	9.7
11. 13 years	1	3.2
12. 14 years	1	3.2
13. 15 years	4	12.9

5. Sex of Hospitalized Child (N=31)

	N	%
1. male	16	51.6
2. female	15	48.4

6. Condition (N=31)

	N	%
1. acute	16	51.6
2. terminal	0	0.0
3. chronic	15	48.3

7. Length of Stay in Hospital (N=31)

	N	%
1. 3 days	13	41.9
2. 4 days	4	12.9
3. 5 days	4	12.9
4. 6 days	2	6.5
5. 7 days	0	0.0
6. 8 days	2	6.5
7. 9 days	1	3.2
8. 10 days	1	3.2
9. 11 days	1	3.2
10. 26 days	1	3.2
11. 27 days	1	3.2
12. 64 days	1	3.2

8. Interview Day (N=31)

	N	%
1. 2	11	35.5
2. 3	8	25.8
3. 4	7	22.6
4. 5	2	6.5
5. 6	0	0.0
6. 7	0	0.0
7. 8	1	3.2
8. 9	2	6.5

9. Number of miles from hospital (N=31)

	N	%
1. under 10 miles	14	45.2
2. 11 to 20 miles	5	16.1
3. 21 to 30 miles	7	22.6
4. 31 to 40 miles	3	9.7
5. 41 to 50 miles	1	3.2
6. 51 to 100 miles	1	3.2
7. over 100 miles	0	0.0

10. Length of time in community (N=31)

	N	%
1. under 6 months	1	3.2
2. 6 months to under 1 year	1	3.2
3. 1 year to under 2 years	3	9.7
4. 2 years to under 3 years	3	9.7
5. 3 years to under 4 years	2	6.5
6. 4 years to under 5 years	1	3.2
7. 5 years or over	20	64.5

11. Number of operating motor vehicles you own (N=31)

	N	%
1. zero	2	6.5
2. one	7	22.6
3. two	12	38.7
4. three	5	16.1
5. four or more	5	16.1

12. Is the area in which you live primarily (N=31)

	N	%
1. rural	16	51.6
2. suburban	13	41.9
3. urban	2	6.5

13. Your marital status (N=31)

	N	%
1. single parent	6	19.4
2. married	21	67.7
3. remarried	4	12.9

14. If married, how many years have you been married (N=25)

	N	%
1. under 1 year	0	0.0
2. 1 year to under 3 years	1	4.0
3. 3 years to under 5 years	1	4.0
4. 5 years to under 10 years	4	16.0
5. 10 years or more	19	76.0

15. If a single parent, how many years have you been a single parent (N=6)

	N	%
1. under 1 year	2	33.3
2. 1 year to under 3 years	1	16.7
3. 3 years to under 5 years	0	0.0
4. 5 years to under 10 years	2	33.3
5. 10 years or more	1	16.7

16. Mother age (N=31)

	N	%
1. 26-30 years	4	12.9
2. 31-35 years	11	35.5
3. 36-40 years	12	38.7
4. 41-45 years	2	6.5
5. 46-50 years	1	3.2
6. 51-55 years	0	0.0
7. 56-60 years	1	3.2
8. 61-65 years	0	0.0
9. 66 or over	0	0.0

17. Mother education (N=31)

	N	%
1. some grade school	1	3.2
2. completed grade school	0	0.0
3. some high school	6	19.4
4. completed high school	14	45.2
5. some college	4	12.9
6. completed college	3	9.7
7. advanced degree after completing four years of college	3	9.7

18. Mother employment status (N=31)

	N	%
1. full-time homemaker	11	35.5
2. employed full time outside the home	13	41.9
3. employed part time outside the home	5	16.1
4. unemployed and looking for work	1	3.2
5. retired	0	0.0
6. full-time student	0	0.0
7. other	1	3.2

19. Mother occupation (N=28)

	N	%
1. professional	5	17.9
2. homemaker	10	35.7
3. skilled	3	10.7
4. unskilled	10	35.7

20. Father age (N=25)

	N	%
1. 26-30	3	12.0
2. 31-35	7	28.0
3. 36-40	8	32.0
4. 41-45	2	8.0
5. 46-50	3	12.0
6. 51-55	1	4.0
7. 56-60	0	0.0
8. 61-65	1	4.0
9. 66 or over	0	0.0

21. Father education (N=25)

	N	%
1. some grade school	3	12.0
2. completed grade school	1	4.0
3. some high school	2	8.0
4. completed high school	10	40.0
5. some college	2	8.0
6. completed college	4	16.0
7. advanced degree after completing four years of college	3	12.0

22. Father employment status (N=25)

	N	%
1. full-time homemaker	0	0.0
2. employed full time outside the home	22	88.0
3. employed part time outside the home	0	0.0
4. unemployed and looking for work	0	0.0
5. retired	2	8.0
6. full-time student	0	0.0
7. other	1	4.0

23. Father occupation (N=23)

	N	%
1. professional	7	30.4
2. homemaker	0	0.0
3. skilled	11	47.8
4. unskilled	5	21.7

24. Size of family (N=31)

	N	%
1. 3 members	4	12.9
2. 4 members	13	41.9
3. 5 members	12	38.7
4. 6 members	1	3.2
5. 7 members	1	3.2

25. Number of children in the family (N=31)

	N	%
1. 2 children	14	45.2
2. 3 children	14	45.2
3. 4 children	2	6.5
4. 5 children	1	3.2

26. Total number of boys in family (N=31)

	N	%
1. 0 boys	5	16.1
2. 1 boy	14	45.2
3. 2 boys	8	25.8
4. 3 boys	3	9.7
5. 4 boys	1	3.2

27. Total number of girls in family (N=31)

	N	%
1. 0 girls	6	19.4
2. 1 girl	12	38.7
3. 2 girls	12	38.7
4. 3 girls	1	3.2

28. Position in family of the hospitalized child (N=31)

	N	%
1. oldest	9	29.0
2. middle	8	25.8
3. youngest	14	45.2

29. Position in family of well sibling (N=31)

	N	%
1. oldest	17	54.8
2. middle	5	16.1
3. youngest	9	29.0

30. Is well sibling interviewed older or younger than hospitalized child (N=31)

	N	%
1. older	22	71.0
2. younger	9	29.0

APPENDIX H. FAMILY MEMBERS' PERCENTAGES OF RESPONSES OF THE 53 QUESTIONS PRESENTED IN ORDER OF HYPOTHESES

Table 15. Percentages for household issues

Question	Well sibling	Mother	Father
1. Hospitalization affected parents' job	(N=31)	(N=26)	(N=15)
1. yes	35.5	30.8	18.8
2. no	64.5	69.2	81.3
2. Since hospitalization, do parents talk about money	(N=29)	(N=26)	(N=16)
1. more	27.6	23.1	12.5
2. same	65.5	73.1	81.3
3. less	6.9	3.8	6.3
3. Traveling to and from the hospital is a problem for parents	(N=31)	(N=26)	(N=16)
1. large problem	9.7	7.7	6.3
2. medium problem	29.0	42.3	31.3
3. no problem	61.3	50.0	62.5

Table 16. Percentages for caregiving issues

Question	Well sibling	Mother	Father
4. Since hospitalization, is someone different caring for well sibling	(N=31)	(N=24)	(N=16)
1. yes	48.4	50.0	43.8
2. no	51.6	50.0	56.3
5. Well sibling cared for where	(N=31)	(N=25)	(N=15)
1. own home	71.0	72.0	81.3
2. someone else's home	29.0	28.0	18.8

Table 17. Percentages for family tasks

Question	Well sibling	Mother	Father
6. Since the hospitalization, have well sibling's chores increased	(N=29)	(N=26)	(N=15)
1. yes	37.9	34.6	31.3
2. no	62.1	65.4	68.8
7. Well sibling has more work in meal preparation	(N=31)	(N=25)	(N=15)
1. yes	41.9	24.0	13.3
2. no	58.1	76.0	86.7
8. Well sibling has more housework or yardwork	(N=31)	(N=26)	(N=16)
1. yes	48.4	23.1	18.8
2. no	51.6	76.9	81.3
9. Well sibling has more work in care of other well siblings	(N=25)	(N=25)	(N=15)
1. yes	44.0	20.0	20.0
2. no	56.0	80.0	80.0
10. Well sibling has more work in caring for him/herself	(N=31)	(N=25)	(N=15)
1. yes	64.5	48.0	26.7
2. no	35.5	52.0	73.3

Table 18. Percentages for affection shown in the family

Question	Well sibling	Mother	Father
16. Since hospitalization, does family like or care about each other	(N=31)	(N=26)	(N=16)
1. more	64.5	38.5	12.5
2. same	35.5	61.5	87.5
3. less	0.0	0.0	0.0
17. Since hospitalization do well siblings get along	(N=25)	(N=20)	(N=15)
1. better	36.0	10.0	13.3
2. same	52.0	90.0	80.0
3. worse	12.0	0.0	6.7

Table 19. Percentages for perceptions of the parents' relationship with the well sibling

Question	Well sibling	Mother	Father
18. Since hospitalization, how does well sibling get along with mom	(N=31)	(N=26)	(N=16)
1. better	19.4	19.2	12.5
2. same	64.5	76.9	87.5
3. worse	16.1	3.8	0.0
19. Since hospitalization, how does well sibling get along with dad	(N=26)	(N=21)	(N=16)
1. better	30.8	19.0	12.5
2. same	69.2	81.0	87.5
3. worse	0.0	0.0	0.0

Table 20. Percentages of the perceptions of parents' relationship with hospitalized child

Question	Well sibling	Mother	Father
20. Since hospitalization, mom and the hospitalized child get along	(N=30)	(N=26)	(N=16)
1. better	73.3	15.4	12.5
2. same	26.7	84.6	87.5
3. worse	0.0	0.0	0.0
21. Since hospitalization, dad and the hospitalized child get along	(N=26)	(N=22)	(N=16)
1. better	46.2	18.2	12.5
2. same	53.8	81.8	87.5
3. worse	0.0	0.0	0.0

Table 21. Percentages of the perceptions of the parents' relationship

Question	Well sibling	Mother	Father
22. Since hospitalization, mom and dad get along	(N=25)	(N=23)	(N=16)
1. better	36.0	4.3	12.5
2. same	64.0	87.0	87.5
3. worse	0.0	8.7	0.0

Table 22. Percentages for family communication

Question	Well sibling	Mother	Father
23. Since hospitalization, family talks to each other	(N=30)	(N=26)	(N=16)
1. more	30.0	15.4	12.5
2. same	53.3	73.1	81.3
3. less	16.7	11.5	6.3
24. Well sibling wishes family would talk about hospitalized child	(N=30)	(N=24)	(N=16)
1. more	16.7	12.5	18.8
2. same	66.7	70.8	75.0
3. less	16.7	16.7	6.3
40. Who told well sibling about hospitalized child's illness	(N=31)	(N=26)	(N=16)
1. mom	45.2	50.0	37.5
2. dad	9.7	3.8	6.3
3. both parents	16.1	30.8	43.8
4. medical staff	3.2	7.7	6.3
5. other	25.8	7.7	0.0
6. parents plus medical staff	0.0	0.0	6.3

Table 23. Percentages of the perceptions of the health attitudes of the well sibling

Question	Well sibling	Mother	Father
25. Since hospitalization, well sibling has had colds	(N=31)	(N=25)	(N=16)
1. yes	6.5	8.0	12.5
2. no	93.5	92.0	87.5
26. Since hospitalization, well sibling has had infections	(N=31)	(N=24)	(N=16)
1. yes	0.0	0.0	0.0
2. no	100.0	100.0	100.0
27. Since hospitalization, well sibling has had headaches	(N=31)	(N=24)	(N=16)
1. yes	22.6	8.3	0.0
2. no	77.4	91.7	100.0
28. Since hospitalization, well sibling has had stomachache	(N=31)	(N=24)	(N=16)
1. yes	22.6	0.0	0.0
2. no	77.4	100.0	100.0
29. Since hospitalization, well sibling has had rashes	(N=31)	(N=24)	(N=16)
1. yes	0.0	0.0	0.0
2. no	100.0	100.0	100.0
30. Since hospitalization, well sibling has had other ailments	(N=7)	(N=15)	(N=16)
1. yes	42.9	0.0	0.0
2. no	57.1	100.0	100.0
31. Well siblings think about getting sick and possibly going to the hospital	(N=29)	(N=24)	(N=16)
1. more	48.3	20.8	25.0
2. same	31.0	62.5	62.5
3. less	20.7	16.7	12.5

Table 24. Percentages of how well siblings perceive their parents

Question	Well sibling	Mother	Father
32. Since hospitalization, mom seems busier	(N=28)	(N=25)	(N=16)
1. yes	60.7	80.0	75.0
2. no	39.3	20.0	25.0
33. Since hospitalization, mom seems	(N=29)	(N=25)	(N=16)
1. more tired	62.1	64.0	56.3
2. same	34.5	36.0	43.8
3. less tired	3.4	0.0	0.0
34. Since hospitalization, mom seems	(N=29)	(N=25)	(N=16)
1. happier	10.3	4.0	12.5
2. same	58.6	64.0	75.0
3. grumpier	31.0	32.0	12.5
35. Since hospitalization, mom seems	(N=30)	(N=25)	(N=16)
1. more worried	70.0	72.0	37.5
2. same	26.7	28.0	56.3
3. less worried	3.3	0.0	6.3
36. Since hospitalization, dad seems busier	(N=21)	(N=22)	(N=16)
1. yes	52.4	54.5	37.5
2. no	47.6	45.5	62.5
37. Since hospitalization, dad seems	(N=23)	(N=21)	(N=16)
1. more tired	39.1	47.6	31.3
2. same	52.2	52.4	68.8
3. less tired	8.7	0.0	0.0
38. Since hospitalization, dad seems	(N=23)	(N=21)	(N=16)
1. happier	8.7	4.8	6.3
2. same	82.6	71.4	75.0
3. grumpier	8.7	23.8	18.8
39. Since hospitalization, dad seems	(N=23)	(N=21)	(N=16)
1. more worried	60.9	47.6	12.5
2. same	34.8	52.4	87.5
3. less worried	4.3	0.0	0.0

Table 24. (continued)

Question	Well sibling	Mother	Father
52. Since hospitalization, well sibling and mom are able to spend	(N=31)	(N=26)	(N=16)
1. more time together	0.0	0.0	6.3
2. same amount of time together	19.4	42.3	43.8
3. less time together	80.6	57.7	50.0
53. Since hospitalization, well sibling and dad are able to spend	(N=24)	(N=22)	(N=16)
1. more time together	16.7	4.5	6.3
2. same amount of time together	41.7	68.2	62.5
3. less time together	41.7	27.3	31.3

Table 25. Percentages of perceptions of how the well siblings perceive themselves

Question	Well sibling	Mother	Father
41. Well sibling is worried about the hospitalized child	(N=30)	(N=26)	(N=16)
1. yes	66.7	80.8	81.3
2. no	33.3	19.2	18.8
42. Well sibling is afraid about having a brother/sister hospitalized	(N=31)	(N=25)	(N=16)
1. yes	45.2	32.0	37.5
2. no	54.8	68.0	62.5
43. Well sibling is afraid s(he) might also get sick	(N=30)	(N=26)	(N=16)
1. yes	43.3	3.8	18.8
2. no	56.7	96.2	81.3
44. Well sibling is jealous about all the attention the hospitalized child is getting	(N=30)	(N=26)	(N=16)
1. yes	26.7	19.2	31.3
2. no	73.3	80.8	68.3
45. Well sibling is jealous about presents ill brother/sister receives	(N=30)	(N=26)	(N=16)
1. yes	20.0	15.4	18.8
2. no	80.0	84.6	81.3
46. Well siblings feels guilty s(he) has a brother/sister in the hospital	(N=30)	(N=26)	(N=16)
1. yes	23.3	15.4	12.5
2. no	76.7	84.6	87.5
47. Well sibling wishes s(he) hadn't fought so much with hospitalized child	(N=31)	(N=25)	(N=16)
1. yes	67.7	24.0	37.5
2. no	32.3	76.0	62.5
48. Well sibling believes it is someone's fault brother/sister is hospitalized	(N=30)	(N=26)	(N=16)
1. yes	23.3	7.7	6.3
2. no	76.7	92.3	93.6

Table 25. (continued)

Question	Well sibling	Mother	Father
49. Well sibling is angry about the attention the hospitalized child receives	(N=31)	(N=26)	(N=16)
1. yes	3.2	3.8	6.3
2. no	96.8	96.2	93.8
50. Well sibling misses hospitalized child	(N=31)	(N=26)	(N=16)
1. yes	87.1	88.5	93.8
2. no	12.9	11.5	6.3
51. Well sibling feels left out about what is happening to hospitalized child	(N=31)	(N=25)	(N=16)
1. yes	41.9	20.0	31.3
2. no	58.1	80.0	68.8

Table 26. Percentages of the perceptions of the well siblings and hospitalized child's relationship previous to hospitalization

Question	Well sibling	Mother	Father
11. Well sibling and hospitalized child did many things together	(N=31)	(N=26)	(N=16)
1. never	6.5	7.7	6.3
2. sometimes	32.3	53.8	31.3
3. often	61.3	38.5	62.5
12. Well sibling and hospitalized child played or horsed around together	(N=31)	(N=26)	(N=16)
1. never	9.7	7.7	0.0
2. sometimes	25.8	57.7	56.3
3. often	64.5	34.6	43.8
13. Well sibling and hospitalized child helped each other with problems	(N=31)	(N=26)	(N=16)
1. never	9.7	11.5	0.0
2. sometimes	48.4	73.1	75.0
3. often	41.9	15.4	25.0
14. Well sibling and hospitalized child got along most of the time	(N=31)	(N=26)	(N=16)
1. never	3.2	3.8	0.0
2. sometimes	29.0	61.5	43.8
3. often	67.7	34.6	56.3
15. Well sibling and hospitalized child argued	(N=31)	(N=25)	(N=16)
1. never	6.5	8.0	12.5
2. sometimes	61.3	72.0	56.3
3. often	32.3	20.0	31.3

APPENDIX I. QUESTIONS TO DETERMINE THE SALIENCY OF THE HOSPITALIZATION ISSUE

Saliency Questions

1. How are things going?
2. Are any new things happening? (If yes, what are they?)
3. Have you been doing what you want lately? (If yes, what have you been doing?)
4. Have things been different lately? (If yes, how have they been different?)
5. What has upset you most recently?
6. What good things and bad things have been happening?
7. Has anything happened you wished hadn't? (If yes, what happened?)
8. Have there been any big changes in the family lately? (If yes, what kind of changes?)
9. How are things with your brother or sister?