THE UNIVERSITY OF MANITOBA

THE PSYCHOSOCIAL ADAPTATION OF SIBLINGS OF CHILDREN WITH CHRONIC MEDICAL ILLNESSES: A REPEATED MEASURES ANALYSIS

by

Sharon Goszer Tritt

A DISSERTATION

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, MANITOBA

1983

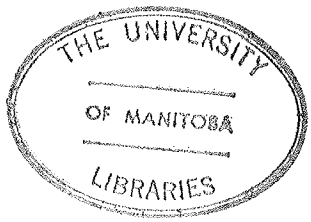
THE PSYCHOSOCIAL ADAPTATION OF SIBLINGS OF CHILDREN WITH CHRONIC MEDICAL ILLNESSES: A REPEATED MEASURES ANALYSIS

BY

SHARON GOSZER TRITT

A thesis submitted to the Faculty of Graduate Studies of
the University of Manitoba in partial fulfillment of the requirements
of the degree of

DOCTOR OF PHILOSOPHY



ACKNOWLEDGEMENTS

I am pleased to acknowledge several people who were instrumental in assisting me to complete this doctoral research project.

Dr. Charles Ferguson, Director of the Ambulatory Care Pediatrics Department of the Children's Centre, provided permission to conduct this study and lead me to the wonderful nursing staff of Children's Clinic who reinforced my notion of the importance of this research topic. Charlotte Siemens and Lesley Galloway, the nurses in charge of the medical clinics which constituted the illness groups I studied, gave generously of their own time to review medical charts and identify the families within which there was a child with a chronic illness.

I would like to thank Drs. Sheldon Koven, William Bowman, and Joe Kettner for agreeing to participate in the formation of the control group. Leona Freedman and Anne Blair, receptionists for these physicians, were most helpful in identifying families and were always friendly and prompt in returning my many telephone calls to them.

Libby Goszer, my research assistant, helped in the collection and scoring of the data. For close to twelve months she was "on call" and almost always prepared to do interviews at short notice. Her interest in this study and kindness to all of the families she interviewed was appreciated.

The chairperson of my doctoral committee, Lillian Esses, has been a continuous source of support and encouragement for me through all the

stages of this dissertation. I would like to thank her for her input into this project and for being my advisor throughout the doctoral program. Always available and empathetic, she was a good friend as well as advisor and took her responsibilities for both seriously. As a member of my committee, Bruce Tefft assisted in the clarification of design and procedural issues. He also directed me to the source of my grant which, in large part, funded this project. I thank him for both of these contributions. Barry Trute served as a member of both my master's and doctoral committee and always was a calming influence for me. His sound advice with respect to research issues and his practical attitude were very helpful to me. I would like to thank Joe Kuypers for his ability to provide criticisms in such a constructive and thought provoking manner. He was the first person to stimulate my thinking about the strengths and positive features of families with a chronically ill child member and I will remember him for that. Although not on my committee, John Lind provided consultation on computer programming and statistical analyses. I would like to thank him for his sage counsel in these areas.

To all the families who volunteered to participate in this study, especially those in which there is a child with a chronic illness, I owe special thanks. This research would not have been possible without their cooperation.

Finally, I would like to acknowledge two very important people in my life--my parents. They have not only loved, supported, and encouraged me in every aspect of my life from the day I was born but they have also taught and developed in me sensitivity to the human condition and acceptance of others. This project is dedicated to them.

TABLE OF CONTENTS

ABSTRACT

The psychosocial adaptation and family functioning of siblings of children with chronic medical illnesses was compared to that of siblings of healthy children at two points in time. The 27 siblings in each group were matched on several demographic variables. Emotional adjustment was assessed through self report measures of anxiety and self concept as well as an interview. Behavioral adjustment was determined by parents' checklist ratings. The role of several variables that may moderate the adjustment of siblings of sick children was also examined. As expected, siblings of ill children had significantly more behavior problems especially in the form of shy-anxious behavior than the control group. The hypothesis of group differences in anxiety level also received support. Contrary to prediction, levels of self concept and family functioning did not differ significantly in the two groups. Level of family functioning and time spent daily by mother in management/treatment activities with the ill child were validated as moderators of adaptation. The role of age of sibling, gender of sibling, and stability of prognosis were not clearly substantiated. Results were discussed in terms of their methodological contribution to the literature, directions for future research, and preventive and interventive implications in families with a chronically ill child member. The limitations of adherence to a purely pathological orientation to the study of the psychosocial adaptation of siblings as well as a homogeneous conceptualization of chronic illness were raised.

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1 - INTRODUCTION

Chronic illness has been defined as a condition persisting for more than three months (Green & Haggerty, 1968a, b). It is also characterized by a high intensity of medical involvement (Grave, 1976). Epidemiological studies of the frequency of chronic illness in childhood reveal variation in reported rates. However, their appears to be general agreement that the total prevalence of chronic conditions in most populations under 18 years of age lies between 10 and 15%, depending on how broad a definition of chronic disease is used and on the methods employed for identification. Froom (1976) states that 6% of the average pediatrician's patients will have chronic problems and 2% of the family physician's patients will be chronically ill children. Illingworth (1964) and Grave (1976) suggest that this rate is increasing in most countries in which there are advanced systems of medical care. They note that sophisticated medical technology is augmenting the survival rate of children with congenital malformations and those with other disorders who, in the past, would have died. The improved prognosis for children with cystic fibrosis (McCollum & Gibson, 1970) and for children with cancer (Mauer, Simone & Pratt, 1977) supports Grave's (1976) and Illingworth's (1964) contention. The data, thus, indicates that chronic childhood illness affects a rather large proportion of the childhood population.[1]

---

[1]See Appendix A for a more lengthy discussion of the literature on epidemiology of childhood chronic illness.

Social scientists and medical clinical investigators involved in studying chronic disease have observed that prolonged illness in children is a source of stress that may pose major problems of adjustment not only for the patient, but also for each individual family member and for the family as a unit (Hymovich, 1976; Kaplan, Smith, Grobstein & Fischman, 1973; Korsch, Negrett, Gardner, Weinstock, Mercer, Grushkin & Fine, 1973; Leiken & Hassakis, 1970; Mattson, 1972; Newell, 1976; Pless, 1973). This is understandable within the family systems framework which asserts that there is an interdependence of family members for satisfaction of their biological, social, psychological and economic needs (Ackerman, 1958; Beavers, 1977; Bowen, 1966; Framo, 1970; French, 1977; Haley, 1967; Minuchin, 1974; Satir, 1971).

Yet, in spite of the fact that investigators have been made aware of the potential implications of ill health for each member of a family as well as for the family unit, the literature discussing chronic illness in children focuses predominantly on the stresses imposed on and adaptations required by the patient and his/her parents. Numerous findings, primarily suggesting maladjustment related to the effects of the illness experience on the part of both the sick child and his/her parents, have been reported in association with several specific disease entities including: leukemia, hemophilia, cystic fibrosis, polio, nephrosis, muscular dystrophy, diabetes, psychiatric disorders, congenital heart disease, asthma, rheumatoid arthritis, and mental retardation (Pfefferbaum, 1978-79; Mattson & Gross, 1965; McCollum & Gibson, 1970; Davis, 1963; Levin, 1970; Vignos, 1968; Weil, 1968; Poznanski, 1969; Lurie, 1968; Rhyne, 1970; Brewer, 1968, Liberthson, 1968; respectively).

Many of these studies are not rigorous in experimental design and there are some discrepancies in the findings reported such that good psychosocial adaptation (or the absence of negative effects) has been observed. Nevertheless, the majority of data is consistent and converges in revealing the potential for emotional and behavioral maladjustment in children with chronic disorders and their parents. It also indicates a strong positive correlation between the adaptation made by parents and that made by the child.

In sharp contrast to the sympathy and attention paid to these family members and the existence of a substantial body of research dedicated to their psychosocial adjustment, the healthy siblings in such families have been virtually ignored. There are a number of reasons why siblings of chronically ill children deserve more attention from researchers. As stated above, serious illness in any family member disturbs the family equilibrium. It may involve alterations in the roles that family members hold; changes in the power structure of the family; splits and coalitions between family members; and changes in family communication patterns (Minuchin, 1974). The available literature on family functioning in relation to having a chronically ill child provides some evidence for each of these effects and reveals that, too frequently, the family revolves around the ill child (e.g., Bolstad, 1974; Crain, Sussman & Weil, 1966; Meyerowitz & Kaplan, 1967; Sigal, Chigoya, Villeneuve & Mayerovitch, 1973). Furthermore, research on the stressfulness of life events for children (Coddington, 1972a, b) defines "psychological trauma" as those events that require a readjustment on the part of the individual or a change in his/her life and has shown that serious illness in a brother or sister ranks quite highly as a source of stress for

children of all ages. Added impetus for the need to assess well siblings of chronically ill children emerges from examination of research documenting sibling maladjustment following the death of a brother or sister. Though Cain, Fast and Erickson (1964) based their findings on an uncontrolled study and clinical data, they observed a number of disturbed reactions in surviving siblings of children who died due to medical illness including: distorted concepts of illness and death and the relationship of these concepts and heightened fears of doctors and hospitals.[2]

In view of each of these separate lines of research and the data suggesting that both the parents of chronically ill children and the afflicted child are at risk for psychosocial maladjustment, one might expect the healthy siblings of chronically ill children to experience psychosocial difficulties. There are, in fact, a few studies which have investigated the adjustment of siblings of ill children. The major findings regarding the impact of chronic illness on the parents, afflicted child, and healthy siblings will be briefly reviewed below.[3]

Psychosocial Adjustment of the Parents of Chronically Ill Children

Certain chronic illnesses are marked by periods of remission and exacerbation, while others do not present such obvious changes in nature over time. Several researchers suggest that the emotional reactions and

---

[2]See Appendix A for a more complete review of the literature on family functioning, stressfulness of life events for children, and sibling reactions to death of a brother/sister.

[3]See Appendix A for a more lengthy review of the literature on the psychosocial adjustment of the parents, ill child, and well-children in families where there exists pediatric chronic illness.

psychosocial adjustment of parents follow the course of the illness (e.g., Mattson, 1979; McCollum & Gibson, 1970). Nevertheless, the parents of children with both of these types of chronic disorders have been observed to display similar affective reactions in response to the diagnosis of chronic illness in their child, including: shock; denial; anxiety; guilt; grief; helplessness; and, a period of intense activity during which time they shop around for medical opinions and for as much information about the disease as possible (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969; Cotter & Schwartz, 1978; Eiser, 1979; Hawke, 1967; Linder, 1970; Meyerowitz & Kaplan, 1967; Raimbault, 1973; Weil, 1968).

Similarly, despite the natural course of the illness, a number of studies have found a high rate of "emotional morbidity" and psychiatric symptomatology severe enough to interfere with adequate functioning amongst parents of chronically ill children. Minde, Hackett, Killou and Silver (1972), for example, studied 41 sets of parents and report that most of them found it difficult to deal with the development of their ill child on a long-term basis. They lived from day-to-day and the majority refused to contemplate the future. Lansky and Gendell (1978) and Lawler, Nakielny and Wright (1966) both document clinical symptoms of depression in the parents they studied, and Gayton, Friedman, Tavormina and Tucker (1977) found increased rates of emotional disturbance, based on MMPI results, in the parents in their investigation when compared to a control group.

Another commonly reported source of stress for parents of children with chronic illness is the daily regimen of in-home therapeutic activities and medical appointments necessitated by certain conditions.

With a diabetic child, for example, blood testing, insulin injection, and diet modifications are a daily requirement (Weil, 1968). For the child who has active rheumatoid arthritis, medication, hot baths, and exercise programs must be adhered to daily (Siemens, Note 1). Some treatment regimens are so demanding that parents have reported curtailment of leisure activities due to a lack of time and energy to engage in such events (e.g., Turk, 1964).

Parents of children with long-term illnesses are also confronted with a variety of other potentially stressful emotionally charged issues. The decision of whether or not to inform the ill child and the well children in the family of the diagnosis is one such issue. The current and ongoing debate amongst health professionals with regard to this does not make the decision easier for parents (see Share, 1972, for an excellent review). Likewise, what to tell relatives and friends regarding the diagnosis and how to handle inappropriate emotional responses to the ill child are frequently expressed sources of parental conflict (Gordon & Kutner, 1965; Meyerowitz & Kaplan, 1967).

In light of the enormous number of stresses created for parents by chronic illness in their child, the accumulation of a sizeable literature on marital disruption in such families does not seem surprising. Though many studies pertaining to the marital relationship of parents of chronically ill children suggests an increased divorce rate (Hamovitch, 1964; Kaplan et al., 1973; Linder, 1970), this conclusion is derived from interview data, clinical impressions and small sample surveys. A few studies have attempted to concentrate on objective variables (such as separation and divorce rates) and/or have rigorously assessed the quality of the marital relationship between parents. These latter investigations

have also employed large samples and comparison groups. The results, however, are not clear cut.

In 191 families with a child who had cancer, for instance, divorce rates were not statistically different from state divorce rates (Lansky, Cairns, Hassanein, Wehr & Lowman, 1978). Increased marital disharmony relative to parents of hemophiliac children and parents of healthy children was revealed though. The marital stress seemed to be associated with the diagnostic stage of the illness and did not increase significantly as a function of time since diagnosis. Death of the child was not associated with divorce. Tew, Laurence, Payne, and Rawnsley (1977), on the other hand, also undertook a longitudinal study and examined the matrimonial stability of 142 families where there was a child with spina bifida. The divorce rate for families with a surviving child was found to be nine times higher than that for the local population, and three times higher than for families experiencing bereavment of their spina bifida child. In this study, in contrast to Lansky et al. (1978) living with a child with spina bifida seemed to result in increased stress and marital disruption over time. Whether the type of chronic illness may be responsible for these discrepant results is uncertain but a plausible hypothesis. What is clear, though, is that regardless of the specific chronic disorder a child has, at some point during the illness many parents do experience stress in their marital relationship which may or may not lead to divorce.

Rigorous study of variables that may influence the type of adaptation made by parents of children with chronic illnesses has not occurred to date. Nevertheless, several variables emerge as possible moderators of parental adjustment. These include the ability to master self-accusatory

and guilt feelings (Mattson, 1972); past experience with crises, death and illness (Adams, 1979; Anthony, 1973; Friedman, 1976; Golan, 1978); age of the child (Farber, 1959; Hamovitch, 1964; Robertson, 1978); socioeconomic status (Murstein, 1960); gender of the child (Farber, 1959; Levine, 1965-66); nature of the illness--life threatening or nonlife threatening (Davis, 1975; Paykel, Note 2) and degree of involvement with the child (Klein, 1975).

Psychosocial Adjustment of Chronically Ill Children

Much evidence exists that some children with chronic illnesses are more vulnerable to psychosocial disturbance than their healthy peers but this evidence is scattered and of variable quality (Cytryn, Moore, & Robinson, 1973; Korsch, 1976; McAnarney, Pless, Satterwhite & Friedman, 1974; Swift, Seidman & Stein, 1967; Zeidel, 1973). There are, however, a growing number of well designed and controlled scientific studies which support this same conclusion.

The three most rigorous and methodologically sophisticated studies of childhood chronic illness (National Survey of Child Health and Development, Schiffer-Hunt, 1963; Isle of Wight Study, Rutter, Tizzard, and Whitmore, 1970; Rochester Child Health Survey, Pless, Roghmann, and Haggerty, 1972) found decreased functioning in chronically ill children when compared to controls, though these findings were not statistically significant. Lags in educational achievement, excess difficulties in social functioning of both an anti-social and withdrawn nature as assessed by a variety of indices, and an increased frequency of psychiatric disturbance were documented in the chronic illness groups. It is Pless and

Roghmann's (1971) conclusion that the data from these three independent investigations show that a high proportion of the social and psychological distrubances must be attributed to the chronicity of the disorders studied. While this conclusion has been questioned by some investigators who suggest that the association could be interpreted as reflecting causality in the reverse direction, i.e., that the emotional disorder is the cause of the physical condition, Pless (Note 3) retorts that "a great deal of common sense and some data exist" to refute this rival psychosomatic hypothesis.

What is most interesting and perhaps quite significant is that in the time since the literature was thoroughly reviewed for the purpose of this dissertation, a few well controlled studies have documented a more positive adaptation than is suggested by the earlier literature (e.g., Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980; Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980). This is not to say that the results available of the psychosocial adjustment of chronically ill children are inconsistent, but rather that the extent of the increased risk of maladjustment may be smaller than previously predicted. Pless (Note 3), in this regard, raises the issue of instrumentation. He points out that many of the measures that have been employed to assess psychosocial adjustment are far from ideal and may actually fail to detect some significant psychosocial concomitants. Given the possible limitations of the measuring tools utilized to date, the proportion of increased risk for chronically ill children is in the range of 2 to $2\frac{1}{2}$ times. Very recently, Pless (Note 3) reported a comparable rate of risk using a well standardized child behavior checklist. These figures, together with earlier risk rates, suggest that as many as 70 or 80% of

children with chronic disorders are free of any emotional difficulties that are detectable with the measures used. The question then becomes, what factors serve to distinguish those children who are most likely to experience such problems from those who are not?

As with the parent population, a number of variables have been suggested as moderators of the type of adjustment made by the child with a chronic illness. These include certain features of the disease: its manner of progression, prognosis, the type of disability it imposes, and its severity. There is, however, a lack of conclusiveness about the importance of these factors. Additionally, certain characteristics of the child, i.e., age and gender, appear to be of relevance in predicting ability to deal with chronic illness. Premorbid personality functioning and temperamental traits are also mentioned in this regard but, due to so few studies of a longitudinal nature, there is little direct evidence to support this. Furthermore, the character of the child's family and the attitudes of the parents, especially the mother (Klein, 1975) seem influential. Pless et al. (1972) were able to predict adjustment problems in chronically ill children when families participating in their research were divided into high and low functioning groups. Earlier suggestions that "specific" diseases were accompanied by characteristic personality disorders have not been supported by controlled research (Pilling, 1973). This will be discussed further in another section of this paper.

Psychosocial Adjustment of Siblings of Chronically Ill Children

There is general consensus among several reports that the siblings

of chronically ill children may actually bear the greatest burden of stress when compared to other family members and receive less support and understanding from their parents and the community at large (Crain et al., 1966; Pless, 1976; Poznanski, 1973). The importance of evaluating behavioral adjustment in the siblings of chronically ill children and the level of stress they experience is emphasized by Grave (1976) and others who have discussed the assessment of outcome in siblings of children with long term illnesses. Furthermore, the need to examine the self-concept of siblings has been indirectly suggested by Pless (Note 3) who postulates a central role for self-concept in generating maladjustment in children afflicted with chronic illnesses. If in fact negative changes in self-concept is the mechanism most likely to operate in producing adjustment problems in the ill child as Pless suggests, the question of whether decreased self-concept may be a key component in the adaptation of healthy siblings or may assist in identifying those most at risk for problems of adjustment must be raised.

Several investigators have found increased rates of maladjustment amongst siblings of mentally retarded children (e.g., Farber, 1959, 1960; Gath, 1973; Tew & Laurence, 1973; Tritt, Note 4), siblings of children with a diagnosis of cancer, (Binger, 1973; Binger et al., 1969; Cairns, Clark & Smith, 1979; Peck, 1979) and siblings of children with other systemic diseases, e.g., asthma, cystic fibrosis, cardiac disorders (Lavigne & Ryan, 1979; Taylor, 1980). Symptoms of both anti-social and shy-anxious behavior have been noted in most of these studies as have feelings of being rejected by parents. Other reactions documented in siblings include increased fighting between well child(ren) and the ill child in the family, jealousy, anger, attention-seeking actions, decline in school performance,

perceptions of parents as over indulgent and overprotective of the sick child, fear of confronting family members with negative feelings, and increased irritability.

However, these findings are of questionable validity and reliability because of the serious methodological shortcomings that characterize the majority of this brief literature. With the exception of a few studies, there is a reliance upon anecdotal evidence and clinical impressions rather than empirical documentation, an absence of adequate controls which eliminate the effects of confounding variables, and employment of inadequate sample sizes and sampling procedures resulting in questionable representativeness of the subjects studied and restricted generalization of results. An equally serious impediment to deriving valid generalizations about the effects of long term childhood illnesses on siblings is the absence of longitudinal research in this regard. Furthermore, there has generally been a failure to enlist appropriate, if any, control groups; data has largely been collected by means of retrospective interviews with parents, physicians, and/or by examination of psychiatric case files; and few studies have used standardized measuring instruments. Consequently, the experiences, feelings, and behaviors of well siblings have not only been based on interviews and questionable measures but, information about healthy siblings has not even been obtained (in most cases) directly from them. This latter flaw may be very significant in light of two of Klein's (1976) findings: that mothers, siblings and children frequently report "different" items about the child's sickness and the family's reactions; and mothers generally "underestimate" the impact of the illness on their well children. Finally, though the available results are quite consistent in their findings

of psychosocial maladjustment in the well siblings of chronically ill children, there are a few reports which suggest the potential for positive adaptation. As with the literature on the ill child, therefore, the question that arises is what factors serve to identify those most likely to have problems?

Several variables that may either alleviate or aggravate the potential adverse effects of having a chronically ill brother/sister have been alluded to in the literature. These include, for example, the age and developmental stage of the well sibling (Levine, 1976); sex of the well sibling (Farber, 1959, 1960; Gath, 1973; Lavigne & Ryan, 1979); life-threatening versus nonlife-threatening nature of the illness (Lavigne & Ryan, 1979); genetic versus non genetic etiology of the illness (Begleiter, Burry & Harris, 1976); and, family functioning (Pless et al., 1972). However, the evidence pertaining to the effects of these possibly influential variables is sparse and has been largely conjectural and/or equivocal. Thus, at present, it is unknown whether any of these variables permit prediction of good or poor adjustment on the part of siblings.

Conceptualization of Chronic Illness: Homogeneity vs Specificity

In the early literature there were numerous suggestions that specific illnesses were accompanied by uniformity in the general personality of those children afflicted with a particular disease. For example, it was alleged that diabetics were more often emotionally labile and aggressive; that children with arthritis displayed a chronic, well-masked state of anxiety; and that asthmatics had trouble showing emotion.

These ideas, however, have not been substantiated over the years and it seems likely that they emanated from unsophistecated research methodology. Pless and Pinkerton (1975) were among the first to advocate, on the basis of their extensive review of the psychosocial effects of childhood chronic illness, that the specific type of illness is not as important as the chronicity factor per se. In the past few years this notion appears to have become accepted, as the most current studies and reports pertinent to the effects of chronic illness are not disease-specific but, rather, focus on groups of illnesses. Though there still seems to be uncertainty as to the most appropriate grouping of illnesses, the current trend is to classify illnesses in terms of broad types of disability, e.g., sensory, cosmetic, medical.

Purpose and Research Hypotheses

The major objective of this research was to more rigorously examine the adjustment of the healthy siblings of children with systemic (medical) chronic illnesses, by utilizing sophisticated experimental methodology including a longitudinal-repeated measures perspective. The temporal nature of the research design was an innovation in the literature on siblings of chronically ill children. Two major areas of adjustment were assessed at two points in time: affective/emotional adjustment and social/behavioral adjustment.

A second purpose was to systematically examine a number of moderator variables in terms of their influence on the psychosocial adjustment of healthy siblings, in the hope that those siblings most at risk for the

development of psychosocial problems could be identified.

Though crisis theory argues that either positively adaptive or negatively adaptive responses may stem from stressful and challenging experiences, this research maintained tradition with the majority of studies available and primarily assumed a pathology orientation in its investigation of the adjustment of siblings of chronically ill children. An opportunity to discuss positively adaptive responses of healthy siblings was provided, however.

The following hypotheses were advanced:

Hypothesis 1. Siblings of children with chronic illnesses will have significantly more emotional and behavioral adjustment problems at both points in time than siblings of children not afflicted with chronic illnesses.

Hypothesis 2. Families in which there is a chronically ill child will report significantly lower levels of family functioning at both points in time than families in which there are no chronically ill children.

Hypothesis 3. Siblings of children with chronic illnesses marked by periods of remission and exacerbation (i.e., unstable prognosis) will have significantly more emotional and behavioral adjustment problems at both points in time than siblings of children with chronic illness not characterized by periods of remission and exacerbation (i.e., stable prognosis).

Hypothesis 4. The greater the amount of time spent by parents in daily management of their chronically ill child, the more emotional and behavioral problems siblings will have at both points in time.

Hypothesis 5. Siblings of chronically ill children with low levels

of family functioning will have significantly more emotional and behavioral adjustment problems at both points in time than siblings of chronically ill children with high levels of family functioning.

Hypothesis 6. The older the siblings of chronically ill children, the more emotional and behavioral adjustment problems they will have at both points in time.

Hypothesis 7. Female siblings of children with chronic illnesses will have significantly more emotional and behavioral adjustment problems at both points in time than male siblings of children with chronic illnesses.

CHAPTER 2 - METHOD

Selection of Pediatric Chronic Illnesses

The first step in the research was to select the pediatric chronic illnesses from which a sample of subjects could be obtained for the purpose of this study. While adopting a nonspecificity conceptualization of chronic illness, in order to achieve greater experimental control, it was decided to select a few "medical" illnesses that were as homogeneous as possible. This was done in consultation with medical and nursing staff at a local pediatric hospital which had expressed interest in this investigation.

Three illnesses were picked for study: Diabetes, Juvenile Rheumatoid Arthritis (JRA) and Gastrointestinal disorders. All three of these illnesses are systemic and have a known biological etiology. In addition, they were judged as having similar implications for the ill child. In all three cases (1) the disease is currently viewed by medical practitioners as being essentially nonlife-threatening, (2) there are prescribed medications and treatments, and (3) parental involvement is frequently necessary. The major differences amongst these three illnesses are that Diabetes has dietary restrictions and is not characterized by periods of remission or exacerbation, whereas the other two diseases do not have prescribed dietary regulations and do have periods of remission and exacerbation. This difference in the natural course of the illness was necessitated by the third hypothesis. Another important reason for choosing

these three particular illnesses was that the physicians and nurses responsible for operating specialty clinics for patients with these diseases expressed willingness to have their patients participate in the research.

Identification of Potential Subjects

The next step was to identify potential subjects for each of the following two groups: families in which there was a child with Diabetes, Juvenile Rheumatoid Arthritis or a Gastrointestinal disorder (index group) and families in which there were no chronically ill or handicapped members (control group). The following inclusion criteria were specified a priori: the family must be of two-parent structure, with at least one non-chronically ill child between the ages of 5 and 18 years in the index group and at least two non-ill children in this age range in the control group. In addition, the family should be Caucasian and have urban residence. The criteria of being a two-parent family, urban residency, and race were employed to prevent confounding of the tests of differences between the two groups by marital status, place of residence, and race. The age criterion for the children permitted a focus on those attending school.

Families in the index group also had to meet the following inclusion criteria which were specified a priori: (1) to be considered "chronically ill", a child had to have been sick for at least three months and receiving treatment on a regular, intensive basis at the Diabetic, Rheumatology, or Gastroenterology specialty clinics of a local, pediatric treatment centre; (2) only one member per family (a child) could have a

chronic illness; (3) diagnosis of the chronic illness must have occurred between three and twelve months prior to initiation of this research; (4) the chronic illness had to be of a "severe" nature, according to operational criteria delineated in advance by the investigator; (5) the appearance of the chronically ill child was not to be noticeably affected by the illness, as judged by medical staff at each of the specialty clinics; and (6) the chronically ill child was to have no record of hospitalizations subsequent to diagnosis.

The above definition of "chronically ill" was used because it concurred with other reports in the literature and, thus, made this study more directly comparable to other studies. The second criterion was specified to eliminate the possible confounding effects of having more than one family member with a chronic illness. In view of the literature demonstrating fairly uniform responses to "diagnosis" of chronic illness (see introduction) and in order to truly examine responses to the "chronic" aspect of the illness, it was seen as necessary to restrict the sample to families who were past the diagnostic stage. Caplan (1974) and Golan (1978) claim that the diagnosis of a chronic illness is a crisis experience and suggest that it normally takes approximately three months for this phase to terminate. Hence, the criterion of families being three months post diagnosis was adopted. The criterion of up to 12 months post diagnosis was seen as desirable in order to study families for whom the chronic illness experience was still relatively new. The severity criterion was enforced to provide for as homogeneous a group as possible; while the appearance criterion was employed because of the literature suggesting that visible malformations or distortions in the appearance

of a chronically ill child may pose greater adjustment requirements for the child and others who come into contact with him/her (Pless & Pinkerton, 1975; Richardson, 1968). Lastly, the hospitalization criterion was specified because of the numerous findings regarding the potentially adverse psychosocial consequences of the hospitalization experience on the ill child and his/her siblings (Adams, 1979; Lewis, 1982) and the possible resulting confounding effects if this variable was not controlled.

Identification of index families. Potential subjects for the group with a chronically ill child family member were identified from the medical charts of all children attending the three selected specialty clinics at the Ambulatory Care Department of the Children's Hospital in Winnipeg, Manitoba. To reduce bias and selection effects, the medical charts for all children attending these clinics were reviewed by the nurse in charge of the clinic. Unfortunately, the nurses found the inclusion criteria to be too restrictive and could only identify five families on their basis. Thus, the criteria for this group of subjects were made less stringent. Nurses were instructed by the investigator to be more lax about the following variables in descending order of importance: time elapsed since diagnosis, number of hospitalizations, place of residence, and race. Subsequently, 25 more potential index subjects became identified, to yield a total of 30 potential index families. All families who met the criteria were contacted by means of a letter (see Appendix B) distributed by the nurse and were asked to fill out a brief questionnaire (see Appendix C) providing the following information:

occupational and employment status of parents; number, age, grade level and gender of all children in the family; whether the healthy child(ren) in the family had been informed of the ill child's chronic condition; and an estimate of the amount of time each parent spends daily in treatment-related activities with the ill child.

Those interested in learning more about the study and possibly participating in it were asked to provide their name, address, and telephone number along with the other information and to return the questionnaire to the investigator in an enclosed, self-addressed, stamped envelope. The medical staff of each clinic were not told which families consented to participate. This procedure was employed to guarantee the anonymity of families who did not wish to partake in the study from the nurses and physicians treating their chronically ill child member. It also ensured the anonymity of families who did not wish to identify themselves to the investigator.

Identification of control families. Potential subjects for the group with no chronically ill or handicapped family members were identified from the medical charts of three local physicians (two with family practices and one with a pediatric practice) who were sent a letter requesting their cooperation in enlisting a matched control group (see Appendix D). In order to reduce bias and selection effects, each physician was asked to select more than one eligible family from his caseload that matched each index family on the following variables: age and gender of the healthy sibling participating in the study, father's occupation and mother's occupation. He was then to randomly send a letter (see Appendix E) to at least one match for each of the index families.

However, problems were experienced in the matching process. All three physicians targeted the variable of mother's occupation as being the biggest impediment to locating control families and, therefore, precise matching on this characteristic was deemed unnecessary. Instead, the physicians were instructed by the investigator to match mothers in the two groups on their employment status, i.e., whether they were employed outside of the home or not. In view of the fact that previous research has only controlled for fathers' occupation and does not seem to have considered mothers' employment, this still seems to be an improvement in experimental rigor. Thirty-eight potential controls were found. These families were contacted by means of a letter (see Appendix E) which was similar in format to that sent to index families and included a brief questionnaire (see Appendix F) containing the same information asked of the index families, with the deletion of the two questions relating to chronic illness. The parents were asked to follow the same procedure as the index parents in returning the questionnaire to the investigator. The physicians were not informed of which families agreed and which declined to participate in the research.

Subject Selection

Though it had been decided a priori that the first 32 families in each group who met all the criteria for eligibility and who consented to participate would constitute the sample, and that subject selection for the index group would be completed prior to selection of families for the control group or collection of any data, this was not the case. Acknowledging that this would have been methodologically ideal and that good

balancing of such important variables as gender and age within the index group could have been achieved this way, the realities of the clinical nature of this investigation and time did not permit such rigorous subject selection procedures. Even given the relaxation of inclusion criteria in the index group, the projected number of families had to be reduced. This was also partially necessitated by the length of time it took to form the index sample. It was decided that a one year time limit was a reasonable attempt at solicitation of subjects for the index group and that all families who met the relaxed inclusion criteria within this time frame would constitute the sample.

As a consequence of the difficulties encountered in obtaining the index group, the procedure for getting control subjects was modified. Thus, in the course of the year defined for subject selection, once an index family was found, all three physicians assisting with formation of the control group were notified of the relevant characteristics of this family and the search for a matched control family began. The first family that returned the questionnaire and met the criteria for inclusion was selected to be part of the control sample.

Once a questionnaire was returned from a family who had been identified as a potential index or control subject, the family was contacted by telephone by the researcher. The purpose of the study and the requirements for participation were clearly described at this time (see Appendix G). Confidentiality of findings was assured. A committment regarding participation was then secured and an appointment for a first interview was scheduled for those who agreed to participate in the study. Those subjects who indicated an interest in participating but who were not selected were sent a letter of thanks for their interest and an explanation (see Appendix H). This only occurred in a few instances in the

control group. All those who replied to the letter were sent a synopsis of the results once the study was completed (see Appendix I).

Response rate and characteristics of index families. The responses from potential subjects for the index group are presented in Table 1. As can be seen, 28 of the 30 families contacted (93.3%) volunteered to participate in the study. However, one family was later found to have more than one child afflicted with a chronic illness and was therefore dropped from the sample, making the total number of index families who volunteered and met the inclusion criteria equal to twenty seven (90%). In two cases (6.7%) questionnaires were not sent back and, since no letters were returned to the sender, these families were considered refusers.

The characteristics of the entire index sample and each of the three illness groups which compose the sample appear in Table 2. As is evident, the three groups do not differ significantly from each other on any of the variables. Thus, they were considered to be quite homogeneous with respect to gender distribution, age, socioeconomic status (SES), time elapsed since diagnosis, number of hospitalizations subsequent to diagnosis, race, and place of residence. However, the mean time elapsed since diagnosis (3 years, 7 months) exceeded that originally proposed. The sample was also homogeneous with respect to severity and visibility of illness, number of family members with a chronic illness, phase of the illness, and family structure.

Response rate and characteristics of control families. The responses from potential subjects for the control group are also presented in Table 1. It is apparent from inspection of this table that fewer families (n = 38)

Table 1

Responses from Index and Control Families

	Index		Control	
Volunteered and met inclusion criteria	27	(90%)	27	(71%)
Volunteered but did not meet inclusion criteria	1	(3.3%)	2	(5.3%)
Non-Responders/Refusals	2	(6.7%)	9	(23.7%)
Letters returned to sender	0	(0%)	0	(0%)
TOTAL	30	(100%)	38	(100%)
Final response rate	93.3%		76.3%	

Table 2

Characteristics of Index Families

Characteristic	Total Sample (N = 27)	Diabetes (N = 11)	JRA (N = 10)	Gastrointestinal (N = 6)	Statistic
Gender					
Female	18	7	6	5	$F(2, 21) = .39$ $p > .05$
Male	9	4	4	1	
Mean age[a]	12-4	12-2	11-9	13-9	$F(2, 21) = .15$ $p > .05$
Mean SES[b]	47.24	50.95	43.45	46.76	$F(2, 21) = 1.45$ $p > .05$
Time since diagnosis[c]	3-7	3-9	3-4	3-9	$F(2, 21) = .22$ $p > .05$
Mean number of hospitalizations	2.65	1.0	< 1.0	3.5	$F(2, 21) = .71$ $p > .05$
Race					
Caucasian	26	11	10	5	F (2, 21) $p > .05$
Non-Caucasian	1	0	0	1	
Place of Residence					
Urban	21	8	8	5	$F(2, 21)$ $p > .05$
Rural	6	3	2	1	

[a] Reported in years and months.
[b] Based on the Blishen (1967) socio-economic index for occupations in Canada.
[c] Reported in years and months.

than were desired for methodological reasons were identified by the physicians assisting with the matching procedure. It was, therefore, fortunate that 27 of the 29 families who volunteered to participate (71%) met the inclusion criteria. In one of the two cases that had to be excluded there was only one child in the family, i.e., no siblings. In the other case, there was a sibling who had a chronic illness which was unknown to the physician because he did not treat this family member.

Examination of Table 1 also reveals that the refusal rate was much higher in the control group (23.7%) than in the index group (6.7%) and that there was a somewhat lower overall rate of response in this group (76.3% vs 93.3%). The most likely explanation for these findings is that this study on pediatric chronic illness had less importance for families which did not have a chronically ill member than for those in which there was a child member afflicted with a chronic disorder.

Final Sample of Families Studied

The final sample consisted of 27 families in the index group and 27 families in the control group. All of the families were Caucasian, except for one black family in the index group. With the exception of six families in the index group, all of the families also had urban residence. In three of these six cases the family lived within a half hour's drive of the city, whereas in the other three cases a much longer distance had to be travelled. Although all families were of two parent structure at the time of the first assessment interview, two families in the index group experienced marital breakdown in between the first and second interviews.

The characteristics of the final sample of families studied are presented in Table 3. A Hotelling T^2 multivariate analysis performed to determine whether there were any significant differences between the index and control groups revealed no differences on the set of demographic and family variables ($T^2(3, 50) = .015$, $p > .05$) and that there was no need to use covariates in future between group analyses. As can be seen by the univariate results, the two groups were well matched on all of the following variables: distribution of male and female siblings and age of the siblings participating in the study, SES as determined by fathers' occupations, employment status of mother, and family size.

The Independent Variable: The Need to Match Experimental and Control Subjects

Due to the fact that the independent variable in this investigation consisted of group membership, i.e., index or control, which was defined in terms of the presence or absence of a chronically ill child family member, field research was necessitated. Consequently, subjects could not be assigned randomly to the two groups and a non-equivalent control group design was imposed. Furthermore, pre-test measures on the dependent variables, obtained prior to the introduction of the independent variable, were not available. While it is acknowledged that causal interpretation of the effects of independent variables on dependent variables is limited with this quasi-experimental approach (Cook & Campbell, 1979; Kenny, 1975), attempts to control for the influence of possibly important extraneous variables that could be invoked as rival explanations for any group differences that emerged, through careful matching of index and control groups, was undertaken as described above.

Table 3

Characteristics of Families Studied

Characteristics	Group: Index	Group: Control	Statistic	
Gender				
Female	18	18	$x^2(1)$	= .00 $p > .05$
Male	9	9		
Age[a]	12-4	12-5	$F(1, 52)$	= .00 $p > .05$
SES[b]	47.24	47.19	$F(1, 52)$	= .00 $p > .05$
Status of mother				
Employed	16	14	$x^2(1)$	= .08 $p > .05$
Not employed	11	13		
Family size	2.59	2.56	$F(1, 52)$	= .04 $p > .05$

[a] Reported in years and months

[b] Based on the Blishen (1967) socio-economic index for occupations in Canada.

Dependent Variables

Two major areas of psychosocial functioning were assessed for the siblings in both the index and control groups: (1) behavioral adjustment (social functioning) which refers to the degree to which the sibling meets societal expectations in various areas of functioning; and (2) emotional adjustment (affective functioning) which refers to how the sibling feels and thinks about herself/himself. In the present investigation, two aspects of emotional adjustment were evaluated. These were self-concept and anxiety.

Dependent Measures

Measures on the well siblings. Four measures were employed to assess the psychosocial adjustment of the siblings.

1. The Behavior Problem Checklist (BPC, Appendix J). The behavioral-social adjustment of the well siblings was assessed by means of the Behavior Problem Checklist developed by Quay and Peterson (Note 5). This measure consists of 55 items describing behavioral adjustment problems of children, each of which was rated on a 3 point scale (no problem, mild problem, or severe problem) by the child's mother and the child's father.

The factorial structure of the scale is consistent with a large body of research which has identified three major dimensions of behavioral maladjustment in children that are relatively independent: shy-anxious behavior (Personality-Problem), anti-social behavior (Conduct-Problem), and immature behavior (Inadequacy-Immaturity) (Peterson, 1961;

Quay, 1972; Quay and Quay, 1965). The score for each subscale is determined by calculating the number of items on the subscale which have been checked as either "mild problem" or "severe problem". This scoring system was used over and above other alternatives that have been suggested since research has shown that it correlates very highly (.98 to .99) with weighted scoring of the mild and severe ratings (Quay & Peterson, Note 5). A high score on each subscale indicates a high degree of behavioral-social adjustment problems.

In a recent article, Quay (1977) comprehensively reviewed the reliability and validity of the BPC. With reference to its reliability, studies examining inter-rater reliability (agreements between parents or teachers) have revealed correlations ranging from .67 to .75 for the Personality-Problem subscale and correlations ranging from .77 to .78 for the Conduct-Problem subscale. Studies examining the test-retest reliability of the scale over short periods of time (e.g., two weeks) have reported even higher reliability estimates. In terms of its validity, the BPC has accurately discriminated between children referred to child guidance clinics and normal children. It has been shown to be sensitive to behavior changes resulting from therapeutic interventions. It has also been found to be significantly related to other measures of behavioral deviance and to academic underachievement.

This particular measure of behavioral adjustment was chosen because it has been successfully utilized in other research investigating the psychosocial adjustment of children (Nelson, Note 6; Tritt, Note 4). Furthermore, reports on the siblings of chronically ill children have infrequently included the use of standardized measuring tools and this has

been described by Grave and Pless (1976) as an area of needed improvement. Nevertheless, in the time since this study was proposed and undertaken, a new child behavior checklist (Achenbach, 1979) seems to have become the most advocated behavioral checklist. This may be related to the fact that it consists of several scales tapping a greater number of dimensions of behavioral adjustment than the BPC.

2. The Self-Appraisal Inventory (SAI, Appendices K, L, M). The Self-Appraisal Inventory (Frith & Narikawa, 1972) was used to assess the self-concept of the siblings who took part in this study. This measuring instrument consists of a range of items which relate to children's subjective feelings in four areas: their family, peer relationships, academic performance, and general well-being. The scale has primary (grades K-3), intermediate (grades 4-6), and secondary (grades 7-12) level forms, consisting of 36, 77, and 62 questions respectively. Questions are responded to on a "yes" or "no" basis. The forms were explained in a standardized format to all of the siblings and they were asked to fill them out by themselves. In the case of young children who could not read the questions, verbal administration occurred. Assistance was also provided to older children, whenever necessary.

Subscale scores are obtained by counting one point for each positive response; that is for each response indicating favorable perceptions of self. Due to the disparate number of questions on the three forms of the SAI, each score was divided by the total number of items for the scale, so as to yield an equivalent scoring system for the three levels. A high score on all of the SAI subscales indicates a high level of emotional-affective adjustment.

Overall test-retest reliability has been estimated at .73 for the

primary level, .88 for the intermediate level, and .87 for the secondary level. The scale has face validity in that the items deal explicitly with how the child feels about himself/herself (e.g., "I'm not very smart"). More rigorous empirical validations have yet to be undertaken. Lastly, the items on the scale are not disguised, allowing the possibility of socially desirable responding. Despite these shortcomings, however, the SAI is one of the only instruments available to assess very young children's evaluations of themselves and which provides comparable forms for children at the primary, intermediate, and secondary grade levels.

3. The What I Think and Feel Questionnaire: Revised Children's Manifest Anxiety Scale (WITF, Appendix N). The What I Think and Feel Questionnaire (Reynolds and Richmond, 1978) was employed to measure the anxiety level of the siblings in this research. It is composed of 37 items that can be answered by children in grades 1 to 12 on a "yes" or "no" basis. It yields both measures of anxiety and a measure of the child's tendency to deny common faults. Once again, standardized instructions were given to all siblings who were then asked to complete the questionnaire on their own. For those children who had difficulty reading the questions, verbal administration took place. Help was also provided to the older children whenever necessary. Subscale scores are determined by summing the number of items on the subscale which have been answered affirmatively. A high score on each of the WITF subscales signifies a high level of anxiety and, therefore, a low level of emotional-affective adjustment.

The factorial structure of the scale is consistent with factor analysis of the original Children's Manifest Anxiety Scale. Three major dimensions of anxiety in children which are relatively independent have

been identified: Physiological manifestations of anxiety, Worry and Oversensitivity, and Fear/Concentration (Reynolds and Richmond, 1979).

The reliability of the WITF scale was examined by Reynolds and Richmond (1978). They report a Kuder Ross 20 reliability estimate of .83 with the item selection sample, and of .85 with a cross-validation sample. These estimates are quite comparable to reliability coefficients reported by Kitano (1960) of .86 and by Finch, Montgomery and Deardorff (1974) of .77. Thus far, early investigations have supported the content (Reynolds and Richmond, 1978), and construct (Reynolds and Richmond, 1979) validity of the new scale.

Reynolds and Richmond (1978) indicate that females display greater anxiety than males. This finding is consistent with previous research utilizing the original CMAS (Bledsoe, 1973; Castaneda, McCandless, & Palmero, 1956) and several other well-known anxiety scales (Sarason, Davidson, Lighthall, Waite & Ruebush, 1960). Although anxiety differences across grade levels are not suggested by Reynolds and Richmond (1978), they have been observed in some previous research with the original scale (Bledsoe, 1973), thus indicating some controversy.

4. Semi-Structured Interview (Appendix O). A semi-structured interview designed by the investigator was administered to siblings in the index group only. The wording and language of the questions was modified to suit the age of the subject interviewed. Several questions were taken and adapted from Klein's (1975) "Sibling Questionnaire" originally devised for study of siblings of children with serious and chronic kidney conditions. According to Klein (1976), her questionnaire is not restricted to use with this one chronic illness and can be employed with a diversity of illnesses. Other questions were formulated on the basis

of clinical hunches derived from case reports and anecdotal comments described in the literature. Areas covered in the interview included: knowledge of the illness, the well-siblings' impression of the impact of the illness on the afflicted child's daily functioning and the ill-child's relationship with parents; perceptions of the effect of the illness on family life and on individual members of the family; and, the negative consequences of having a chronically ill brother or sister on the well-sibling. The interview also provided opportunities for the well siblings to identify any positive effects and/or gains made through the experience of living with a chronically ill brother or sister. The final question in the interview was of a projective nature and asked well siblings what type of advice they would give to other children who had just been informed that a brother or sister of theirs was diagnosed as having a chronic medical condition. Given that the chances of socially desirable responses being provided were escalated with an interview type of measurement procedure, it was hoped that this indirect, projective question would provide a less defensive reply.

Measures on the family. There was one measure on the family.

1. The Family Functioning Index (FFI, Appendix P). The Family Functioning Index developed by Pless and Satterwhite (1973) was employed to assess family functioning in both the index and control groups. It is composed of 15 questions chosen to reflect the dynamics of family interaction. Zero, one, or two points are assigned to each response depending on the degree to which the answer is congruent with presumed optimal functioning. A total score is obtained by the addition of scores for each question. Higher scores reflect more desirable levels of

functioning.

Factor analysis of the FFI reveals six principal components including: "marital satisfaction", "frequency of disagreements", "communications", "problem solving", "feelings of happiness" and "closeness". With the exception of the "problem solving" category, these components all have a strong correlation with total index scores ranging from .34 up to .95 (Pless and Satterwhite).

Three means of validation have been reported by Pless and Satterwhite for the FFI. Correlations between case workers' at professional family counseling agencies and husbands' and wives' independent ratings indicate significant agreement: $\underline{r} = .35$, $\underline{p} < 0.013$ and $\underline{r} = .48$, $\underline{p} < .01$, respectively. A second validation incorporated similar independent ratings made by six non-professional counselors who had been assigned to families with a chronically sick child which constituted the sample on which the index was originally tested. A correlation of .39 ($\underline{p} < .001$) was obtained. A final estimate of validity is provided through a comparison of the mean score of the original sample with that of the sample from the professional counseling agencies. Because the latter group was seeking assistance for family problems, it was hypothesized that the mean FFI score for this group would be appreciably lower. Statistical testing confirmed this prediction.

Convergent validity of the index is revealed by the correlation of .72 ($\underline{p} < .001$) between the FFI scores of husbands and wives attained independently (Pless et al., 1972). Furthermore, a five year test-retest reliability of .83 ($\underline{p} < .001$) between the original and retest FFI total scores (Satterwhite, Zweig, Iker & Pless, 1976) is very high and suggests remarkable stability.

Furthermore with respect to validity, Pless and colleagues (1972) found that FFI scores provided a discriminating dimension which few clinical characteristics were able to achieve. In a multiple regression analysis, FFI scores gave the largest part of the explained variance. In addition, chronically ill children were classified into high and low risk groups for the development of psychosocial difficulties on the basis of FFI scores. Children from families with lower scores on this index constituted more of a risk than those from families with higher scores.

At the time this study was proposed, the FFI appeared to be the instrument of choice for measuring family functioning. It had been successfully used in other research investigating the impact of chronic illness, has respectable reliability and validity, and could be quickly administered and scored.

Moderator Variables

In this study, a number of variables that may moderate the psychosocial adjustment of the well-siblings of chronically ill children were examined. They included the following:

Gender. Comparisons between the adjustment of male and female siblings on each of the emotional and behavioral measures were made.

Age. The relationship between the chronological age of the well siblings and functioning on each of the emotional and behavioral measures was assessed.

Family Functioning. Families in the index sample were divided into two groups on the basis of whether their FFI score fell above or below the midpoint of the distribution. Those whose scores fell below the

median constituted the low functioning group, whereas those whose scores were above the median comprised the high functioning group. The emotional and behavioral adjustment of the siblings in these two groups were then compared.

Degree of parental involvement in daily management of the chronically ill child. The relationship between the amount of time spent daily by each parent in activities dictated by the chronically ill child's condition and the emotional and behavioral functioning of well siblings was evaluated. In order to determine the amount of time spent by each parent, mothers and fathers in the index group were asked a brief set of standard questions (Appendix Q). This set of questions was designed by the investigator due to unfamiliarity with any standardized scales with which to assess this variable. When necessary, the Activities of Daily Living inventory (ADL) was used to supplement the information obtained from the investigator's questioning (Appendix R).

Whether the illness is characterized by remissions and exacerbations. Comparisons between the siblings of children with JRA and Gastrointestinal disorders and the siblings of children with Diabetes on the emotional and behavioral adjustment measures were performed in an attempt to see whether this characteristic of the illness had implications for psychosocial functioning.

Interview Procedure

Two appointments for interviews, scheduled three months apart, were booked for each family who consented to participate in the study. All interviews were conducted by a trained interviewer who was an honours

student in psychology and the investigator. The interviewer received two training sessions devoted to explicit delineation of the interview procedure and familiarization with it and the measurement instruments to be employed. With the exception of six interviews which occured in the investigator's office in a building attached to the Ambulatory Care Department of the hospital (three index families who lived a great distance from the city), all interviews took place in the families' homes. The interviews for index families ranged in length from one and a half to three hours, while those for control families generally lasted one hour. All interviews were completed in the one-year period from November 1981 to November 1982. Interviewer bias was minimized by the fact that assessment on all of the dependent and moderator variables was achieved by self-report techniques or by ratings of other family members (i.e., parents' ratings of their children's behavior).

The first scheduled appointment began with the interviewer providing a further explanation of the nature of the investigation to both the parents and the well sibling in the family and attempting to establish rapport. Since one of the underlying assumptions of the study was an awareness of the illness within the index group families, the next step was to probe into the understanding parents in this group had about the chronic illness their child was afflicted with and to get some idea of how informed the well sibling was regarding the illness. It had been decided a priori that any families which were extremely ignorant about the disease and its treatment implications would be eliminated from the study. However, no families had to be excluded on this basis. All parents in both groups were then asked to sign a consent form (Appendix S). Following this, parents in the index group were asked the set of questions

relating to the amount of time they spend daily with their ill child. All parents were asked for a description of the leisure activities engaged in with the well sibling and an estimate of the time spent daily with this child. Next, the BPC and FFI were explained to parents. Both mothers and fathers were asked to independently complete a BPC form for the identified sibling in the family participating as a subject, and to independently fill out the FFI. While the parents were completing these assessment instruments, the interviewer explained the WITF and SAI to the children and asked them to complete each form by themselves. Both of these measures were administered orally to any children who could not read. The interviewer also answered any questions the parents or children had regarding completion of the assessment instruments. Siblings in the index group were subsequently administered the semi-structured interview. After the parents and the sibling finished completing all of the assessment instruments, the interviewer spent a few minutes further discussing the study with the family and then reminded them of the second interview date.

Two weeks prior to the second scheduled interview, the investigator telephoned the family to confirm the appointment. The same procedure as at the first interview was followed at the time of the second interview with three exceptions. Parents in the index group were not questioned about their understanding of the chronic illness or the amount of time spent in treatment-related activities. Nor were parents in either group asked for an estimate of the amount of time they spent with the well sibling partaking in the study. However, each family was asked a set of questions devised by the investigator (Appendix T) aimed at assessing whether any significant changes had occurred in the three month period

in between appointments. This set of questions was asked before any of the formal assessment instruments were to be filled out. At the end of the appointment, the family was thanked for their cooperation and reminded that they would be sent a brief summary of the results of the study when it was completed.

CHAPTER 3 - RESULTS

Due to the longitudinal nature of the research design, repeated measures analyses were performed to test the hypotheses advanced. For each hypothesis proposing between group differences, a two group repeated measures analysis of variance was employed. In view of the fact that (a) more than one dependent variable was specified in terms of sibling adjustment (emotional adjustment; behavioral adjustment), (b) there were two measures of the former and one of the latter, and (c) each dependent measure was composed of subscales which were of interest to the investigator, the multivariate test of group differences was used. Originally, one large analysis including all three dependent measures and the subscales comprising each was intended for the purpose of reducing the rate of error. However, given the sample size, this was not statistically feasible. Therefore, three separate analyses were conducted to examine differences between siblings in the two groups. The hypotheses pertaining to family functioning and stability of prognosis as moderator variables of sibling adjustment within the index group were similarly examined by three separate multivariate analyses. Canonical correlation and Pearson correlation analyses were performed to investigate the hypotheses pertaining to all other moderator variables.

All between group differences were tested at $\alpha = .05$ level of significance. When a multivariate test was significant, univariate results were inspected to determine the significance, if any, of each subscale of the dependent measure independently. In such cases, the

Bonferroni adjustment procedure (α level divided according to the number of univariate tests conducted) was implemented to ensure rigorous control of the error rate (Spinner, Note 7). Post-hoc probing of significant univariate tests and other findings of interest was accomplished by examination of means, variances, and standard deviations on the relevant variables.[1]

Between Group Differences - The Siblings

Hypothesis 1

According to the first hypothesis, siblings of children with chronic illnesses would have significantly more emotional and behavioral adjustment problems at both points in time than siblings of children not afflicted with the chronic illnesses. A summary of the scores of siblings in each group on the dependent measures at each point in time is presented in Table 4.

SAI Subscales. The results of the multivariate analysis of variance on the four SAI subscales as a set do not support the expected relationship between group membership and self-concept at either point in time. As can be seen in Tables 5, 6, and 7 which present the results of this analysis, none of the main effects or interaction effects were statistically significant, with the exception of the main effect for Age of the sibling, F (4, 42) = 7.15, p = .00.

---

[1]All multivariate and univariate analyses of variance, canonical and pearson correlations, and post-hoc testing were done using programs from the second edition of the Statistical Package for the Social Sciences and Supplement of the Statistical Package for the Social Sciences.

Table 4

Scores on Dependent Measures by Group and Time

Group / Index	Time 1 $\bar{X}$	Time 1 SD	Time 2 $\bar{X}$	Time 2 SD
SAI[a]				
General	.70	.14	.69	.14
Peer	.64	.17	.66	.19
School	.71	.13	.69	.16
Family	.68	.18	.71	.15
WITF[b]				
Physiological	3.22	2.14	3.27	2.36
Worry-Oversensitivity	4.07	2.93	3.46	3.01
Fear-Concentration	2.96	2.39	2.39	2.86
Defense-Lie	3.04	3.08	2.62	2.98
BPC[b]				
Personality-Problem	8.48	5.59	7.96	5.92
Conduct-Problem	10.82	8.05	7.96	6.42
Inadequacy-Immaturity	2.74	2.47	2.00	2.29
Control				
SAI				
General	.68	.17	.70	.15
Peer	.69	.18	.71	.15
School	.71	.17	.72	.17
Family	.69	.19	.70	.14
WITF				
Physiological	3.00	2.15	2.96	2.26
Worry-Oversensitivity	4.67	3.06	3.44	3.07
Fear-Concentration	2.52	2.23	2.22	1.81
Defense-Lie	2.63	2.37	1.89	1.97
BPC				
Personality-Problem	4.63	3.12	4.19	3.35
Conduct-Problem	7.93	6.34	7.19	6.52
Inadequacy-Immaturity	1.44	1.78	1.37	1.55

Note. [a]Higher scores indicate better adjustment.
[b]Higher scores indicate poorer adjustment.

Table 5

Summary of the Multivariate Analysis of Variance Main Effects on Self-Appraisal Inventory Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group				
Multivariate T		4, 42	.54	
General	.00	1, 45	.05	
Peer	.07	1, 45	1.36	
School	.00	1, 45	.09	
Family	.00	1, 45	.00	
Age				
Multivariate T		4, 42	7.15	.05
General	.54	1, 45	18.49	.013
Peer	.04	1, 45	.92	
School	.06	1, 45	1.35	
Family	.80	1, 45	23.68	0.13
Sex				
Multivariate T		4, 42	1.16	
General	.04	1, 45	1.59	
Peer	.03	1, 45	.58	
School	.02	1, 45	.70	
Family	.00	1, 45	.02	
Time				
Multivariate T		4, 42	.30	
General	.00	1, 45	.32	
Peer	.01	1, 45	.62	
School	.00	1, 45	.01	
Family	.01	1, 45	.67	

Table 6

Summary of the Multivariate Analysis of Variance Two-Way Interactions on Self-Appraisal Inventory Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age				
Multivariate T		4, 42	.32	
General	.00	1, 45	.31	
Peer	.01	1, 45	.28	
School	.00	1, 45	.03	
Family	.00	1, 45	.09	
Group x Sex				
Multivariate T		4, 42	.54	
General	.00	1, 45	.10	
Peer	.04	1, 45	.89	
School	.01	1, 45	.18	
Family	.01	1, 45	.42	
Group x Time				
Multivariate T		4, 42	.76	
General	.01	1, 45	.89	
Peer	.00	1, 45	.05	
School	.00	1, 45	.33	
Family	.00	1, 45	.31	
Age x Sex				
Multivariate T		4, 42	.86	
General	.00	1, 45	.07	
Peer	.00	1, 45	.10	
School	.00	1, 45	.17	
Family	.06	1, 45	1.70	
Age x Time				
Multivariate T		4, 42	.11	
General	.00	1, 45	.18	
Peer	.00	1, 45	.08	
School	.00	1, 45	.08	
Family	.00	1, 45	.01	
Sex x Time				
Multivariate T		4, 42	.58	
General	.00	1, 45	.29	
Peer	.00	1, 45	.02	
School	.00	1, 45	.14	
Family	.01	1, 45	.83	

Table 7

Summary of the Multivariate Analysis of Variance Higher-Order Interactions on Self-Appraisal Inventory Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age x Sex				
Multivariate T		4, 42	.52	
General	.03	1, 45	1.02	
Peer	.00	1, 45	.02	
School	.02	1, 45	.38	
Family	.00	1, 45	.10	
Group x Age x Time				
Multivariate T		4, 42	1.57	
General	.02	1, 45	1.93	
Peer	.01	1, 45	1.14	
School	.01	1, 45	.92	
Family	.03	1, 45	3.20	
Group x Sex x Time				
Multivariate T		4, 42	.36	
General	.01	1, 45	.79	
Peer	.00	1, 45	.03	
School	.01	1, 45	.48	
Family	.01	1, 45	.63	
Age x Sex x Time				
Multivariate T		4, 42	1.51	
General	.02	1, 45	2.32	
Peer	.00	1, 45	.00	
School	.00	1, 45	.00	
Family	.01	1, 45	1.17	
Group x Age x Sex x Time				
Multivariate T		4, 42	.09	
General	.00	1, 45	.17	
Peer	.00	1, 45	.21	
School	.00	1, 45	.01	
Family	.00	1, 45	.02	

Follow-up of the significant multivariate Age effect via examination of the univariate analyses revealed that both the General and Family subscales were univariate significant: $F(1, 45) = 18.49$, $p = .000$ and $F(1, 45) = 23.68$, $p = .000$, respectively. Table 8 contains the mean scores on each subscale of the SAI for the two age categories of siblings represented in this analysis averaged across group. Examination of this table provides additional clarification of the significant Age effect. It shows that, at both data points, the younger siblings rated their self-concepts on all four SAI subscales and especially the General and Family subscales higher than did the older group of siblings.

In summary, contrary to prediction, siblings of chronically ill children did not report significantly lower levels of self-esteem at either point in time than siblings of children not afflicted with chronic illness. The only significant result with respect to this measure of affective/emotional adjustment related to age. In both groups and at both points in time, the older the sibling, the lower his/her reported self-esteem, especially on the General and Family subscales of the SAI.

WITF Subscales. The results of the multivariate analysis of variance performed on the four WITF subscales as a set provide partial substantiation of the hypothesis relating group membership to emotional adjustment. A summary of this analysis is given in Tables 9, 10, and 11. They reveal that there was a significant Time main effect, $F(4, 42) = 5.46$, $p = .001$, as well as a significant interaction among Group, Sex, and Time, $F(4, 42) = 3.39$, $p = .017$.

Further probing into the multivariate Time effect took place by inspecting the univariate results for each of the WITF subscales. As is evident in Table 9, the Worry-Oversensitivity (WO) subscale was

Table 8

Mean Self-Appraisal Inventory Subscale Scores for Siblings in Different Age Categories

Age category	n	Score							
		General		Peer		School		Family	
		T_1	T_2	T_1	T_2	T_1	T_2	T_1	T_2
Grades K-6	30	.75	.76	.68	.70	.73	.73	.76	.78
Grades 7-12	24	.61	.62	.64	.66	.69	.68	.59	.61

Table 9

Summary of the Multivariate Analysis of Variance Main Effects on What I Think and Feel Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group				
Multivariate T		4, 42	.50	
Physiological	1.91	1, 45	.21	
Worry-Oversensitivity	1.63	1, 45	.10	
Fear-Concentration	2.75	1, 45	.28	
Defense-Lie	8.54	1, 45	.82	
Age				
Multivariate T		4, 42	3.74	.05
Physiological	6.00	1, 45	.66	
Worry-Oversensitivity	.70	1, 45	.04	
Fear-Concentration	26.75	1, 45	2.75	
Defense-Lie	84.38	1, 45	8.09	.013
Sex				
Multivariate T		4, 42	.13	
Physiological	.46	1, 45	.05	
Worry-Oversensitivity	1.77	1, 45	.11	
Fear-Concentration	3.75	1, 45	.38	
Defense-Lie	.00	1, 45	.00	
Time				
Multivariate T		4, 42	5.46	.05
Physiological	.00	1, 45	.00	
Worry-Oversensitivity	24.54	1, 45	7.02	.013
Fear-Concentration	5.43	1, 45	2.94	
Defense-Lie	9.07	1, 45	4.48	

Table 10

Summary of the Multivariate Analysis of Variance Two-Way Interactions on What I Think and Feel Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age				
Multivariate T		4, 42	.49	
Physiological	.20	1, 45	.02	
Worry-Oversensitivity	3.04	1, 45	.19	
Fear-Concentration	1.06	1, 45	.11	
Defense-Lie	11.48	1, 45	1.10	
Group x Sex				
Multivariate T		4, 42	.83	
Physiological	4.20	1, 45	.46	
Worry-Oversensitivity	3.84	1, 45	.24	
Fear-Concentration	6.33	1, 45	.65	
Defense-Lie	7.09	1, 45	.68	
Group x Time				
Multivariate T		4, 42	.45	
Physiological	.04	1, 45	.02	
Worry-Oversensitivity	1.86	1, 45	.53	
Fear-Concentration	.67	1, 45	.36	
Defense-Lie	.67	1, 45	.33	
Age x Sex				
Multivariate T		4, 42	.52	
Physiological	4.50	1, 45	.49	
Worry-Oversensitivity	3.46	1, 45	.21	
Fear-Concentration	.31	1, 45	.03	
Defense-Lie	10.36	1, 45	.99	
Age x Time				
Multivariate T		4, 42	1.59	
Physiological	.95	1, 45	.56	
Worry-Oversensitivity	.60	1, 45	.17	
Fear-Concentration	.16	1, 45	.09	
Defense-Lie	8.53	1, 45	4.21	
Sex x Time				
Multivariate T		4, 42	.22	
Physiological	.04	1, 45	.02	
Worry-Oversensitivity	1.66	1, 45	.47	
Fear-Concentration	.14	1, 45	.08	
Defense-Lie	.08	1, 45	.04	

Table 11

Summary of the Multivariate Analysis of Variance Higher-Order Interactions on What I Think and Feel Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age x Sex				
Multivariate T		4, 42	.81	
Physiological	.03	1, 45	.00	
Worry-Oversensitivity	6.81	1, 45	.42	
Fear-Concentration	5.16	1, 45	.53	
Defense-Lie	11.54	1, 45	1.11	
Group x Age x Time				
Multivariate T		4, 42	.19	
Physiological	.15	1, 45	.09	
Worry-Oversensitivity	.02	1, 45	.01	
Fear-Concentration	.06	1, 45	.03	
Defense-Lie	.80	1, 45	.40	
Group x Sex x Time				
Multivariate T		4, 42	3.39	.05
Physiological	1.39	1, 45	.81	
Worry-Oversensitivity	8.67	1, 45	2.48	
Fear-Concentration	.03	1, 45	.02	
Defense-Lie	11.81	1, 45	5.83	
Age x Sex x Time				
Multivariate T		4, 42	2.30	
Physiological	3.13	1, 45	1.81	
Worry-Oversensitivity	.41	1, 45	.12	
Fear-Concentration	.12	1, 45	.07	
Defense-Lie	9.25	1, 45	4.57	
Group x Age x Sex x Time				
Multivariate T		4, 42	2.22	
Physiological	.71	1, 45	.41	
Worry-Oversensitivity	11.47	1, 45	3.28	
Fear-Concentration	.08	1, 45	.05	
Defense-Lie	.20	1, 45	.10	

significant, F (1, 45) = 7.02, p = .011, suggesting that averaged across groups there was a significant difference in the degree of anxiety reported on this subscale at Time 1 and Time 2. Table 12 contains the combined mean scores of siblings in the two groups on the four WITF subscales at each data collection point. Though all scores at Time 2 were lower than at Time 1, or stayed the same, the greatest decrement over time occurred on the WO subscale.

With respect to the significant multivariate interaction (Group x Sex x Time), follow-up via examination of univariate results yielded no additional information as none of the individual subscales was significant.

There was also a significant Age main effect for the WITF subscales, F (4, 42) = 3.74, p = .011. Again, the multivariate significant effect was probed via univariate analyses. The DL subscale was found to be univariate significant, F (1, 45) = 8.09, p = .007, indicating that, averaged across group, there was a significant difference between older and younger children on this scale of the WITF. More explicit delineation of this finding is available in Table 13 which contains the mean scores on the subscales of the WITF for siblings in the two age categories. It is evident that the younger siblings rated themselves as having higher levels of anxiety on most subscales at both points in time and that their defensiveness scores in particular, were much higher than those of the older siblings at both time periods.

To summarize, support for the hypothesis that siblings of chronically ill children would experience more anxiety than the control group occurred only for the set of WITF subscales and when Sex of sibling and Time were taken into account. None of the individual subscales was univariate

Table 12

Mean What I Think and Feel Subscale Scores

at Different Points in Time Averaged Across Group

	Time		
	Time 1	Time 2	Difference
Subscale			
Physiological	3.11	3.11	.00
Worry-Oversensitivity	4.37	3.45	-.92
Fear-Concentration	2.74	2.30	-.44
Defense-Lie	2.83	2.25	-.58

Table 13

Mean What I Think and Feel Subscale Scores
for Siblings in Different Age Categories

Age Category	n	Score							
		Physiological		Worry-Oversensitivity		Fear-Concentration		Defense-Lie	
		T_1	T_2	T_1	T_2	T_1	T_2	T_1	T_2
Grade K-6	30	3.23	3.41	4.33	3.31	3.13	2.79	3.87	2.79
Grade 7-12	24	2.96	2.75	4.42	3.63	2.25	1.71	1.54	1.58

Note. T_1 is the abbreviation for Time 1
T_2 is the abbreviation for Time 2

significant and, thus, a clear picture of the nature of this effect was not available. In addition, when averaged across group, WO scores decreased significantly over time and younger siblings had higher defensiveness scores than older siblings.

BPC Subscales. The multivariate analysis of variance performed on the three BPC subscales as a set was based on the combined BPC subscale scores of mothers and fathers in each group at each point in time. This step was taken as a result of the findings of a series of correlated t-tests (presented in Table 14) conducted to determine whether the ratings of mothers and fathers within each group differed on any of the subscales. In order to control for the rate of error, the Bonferroni adjustment procedure was applied. As can be seen in Table 14, mothers and fathers within both the index group and the control group did not differ significantly from each other on any of their BPC subscale ratings at either Time 1 or Time 2.

The results of the multivariate analysis of variance appear in Tables 15, 16, and 17. From inspection of the tables one can see that there was a significant main effect for Group, $F(3, 42) = 3.00$, $p = .041$, supporting the predicted relationship between group membership and behavioral adjustment problems. Follow-up of this significant effect through examination of the univariate results for each subscale revealed that the only significant univariate finding was on the Personality-Problem (PP) subscale, $F(1, 44) = 8.14$, $p = .007$. Therefore, while there were significant differences between the two groups of parents in the number of behaviors indicative of Personality-Problems that they perceived in their healthy children, their ratings did not differ significantly from each other in terms of the Conduct-Problem (CP) or Inadequacy-Immaturity (II) subscales. This can be confirmed by referring to the mean scores of the two groups on the BPC measure in Table 4. An increased incidence on the Personality-Problem subscale in the index group at both points in time

Table 14

Results of Correlated t-Tests Performed on Mothers' and Fathers' Behavior Problem Checklist Subscale Ratings at Time 1 and Time 2

GROUP	TIME	SUBSCALE PP t value	df	p	CP t value	df	p	II t value	df	p
Index										
	Time 1	.29	26	.77	1.96	26	.06	-.23	26	.82
	Time 2	1.15	24	.26	2.40	24	.02	.26	24	.80
Control										
	Time 1	.92	26	.37	.54	26	.60	-.62	26	.54
	Time 2	.57	26	.57	.52	26	.61	.94	26	.36

Note. Bonferroni procedure applied in order to control for rate of error.

Table 15

Summary of the Multivariate Analysis of Variance Main Effects on Behavior Problem Checklist Scores of Siblings from the Two Groups

SOURCE	MS	df	F	$p \leq$
Group				
Multivariate T		3, 42	3.00	.05
Personality-Problem	335.08	1, 44	8.14	.017
Conduct-Problem	44.18	1, 44	.50	
Inadequacy-Immaturity	18.00	1, 44	2.26	
Age				
Multivariate T		3, 42	.07	
Personality-Problem	.55	1, 44	.01	
Conduct-Problem	13.95	1, 44	.16	
Inadequacy-Immaturity	.09	1, 44	.01	
Sex				
Multivariate T		3, 42	.26	
Personality-Problem	30.21	1, 44	.73	
Conduct-Problem	10.54	1, 44	.12	
Inadequacy-Immaturity	1.16	1, 44	.15	
Time				
Multivariate T		3, 42	2.37	
Personality-Problem	1.88	1, 44	.37	
Conduct-Problem	40.63	1, 44	6.86	.017
Inadequacy-Immaturity	1.88	1, 44	1.36	

Table 16

Summary of the Multivariate Analysis of Variance Two-Way Interactions on Behavior Problem Checklist Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age				
Multivariate T		3, 42	1.00	
Personality-Problem	18.72	1, 44	.45	
Conduct-Problem	162.42	1, 44	1.83	
Inadequacy-Immaturity	.61	1, 44	.08	
Group x Sex				
Multivariate T		3, 42	1.04	
Personality-Problem	18.62	1, 44	.45	
Conduct-Problem	5.71	1, 44	.06	
Inadequacy-Immaturity	15.31	1, 44	1.92	
Group x Time				
Multivariate T		3, 42	.91	
Personality-Problem	.86	1, 44	.17	
Conduct-Problem	7.28	1, 44	1.23	
Inadequacy-Immaturity	1.07	1, 44	.77	
Age x Sex				
Multivariate T		3, 42	.90	
Personality-Problem	19.04	1, 44	.46	
Conduct-Problem	33.94	1, 44	.38	
Inadequacy-Immaturity	.81	1, 44	.10	
Age x Time				
Multivariate T		3, 42	.27	
Personality-Problem	2.66	1, 44	.53	
Conduct-Problem	1.17	1, 44	.20	
Inadequacy-Immaturity	.84	1, 44	.61	
Sex x Time				
Multivariate T		3, 42	.61	
Personality-Problem	.87	1, 44	.17	
Conduct-Problem	.04	1, 44	.01	
Inadequacy-Immaturity	2.49	1, 44	1.80	

Table 17

Summary of the Multivariate Analysis of Variance Higher-Order Interactions on Behavior Problem Checklist Scores of Siblings from the Two Groups

SOURCE	MS	df	F	p≤
Group x Age x Sex				
Multivariate T		3, 42	.78	
Personality-Problem	.23	1, 44	.01	
Conduct-Problem	135.70	1, 44	1.53	
Inadequacy-Immaturity	2.16	1, 44	.27	
Group x Age x Time				
Multivariate T		3, 42	2.30	
Personality-Problem	2.50	1, 44	.49	
Conduct-Problem	15.37	1, 44	2.60	
Inadequacy-Immaturity	3.24	1, 44	2.34	
Group x Sex x Time				
Multivariate T		3, 42	.57	
Personality-Problem	.51	1, 44	.10	
Conduct-Problem	.30	1, 44	.05	
Inadequacy-Immaturity	1.92	1, 44	1.39	
Age x Sex x Time				
Multivariate T		3, 42	.42	
Personality-Problem	3.24	1, 44	.64	
Conduct-Problem	.18	1, 44	.03	
Inadequacy-Immaturity	.77	1, 44	.56	
Group x Age x Sex x Time				
Multivariate T		3, 42	1.38	
Personality-Problem	.21	1, 44	.04	
Conduct-Problem	21.88	1, 44	3.69	
Inadequacy-Immaturity	.96	1, 44	.70	

is clear, as is little difference between groups on the Conduct-Problem and Inadequacy-Immaturity subscales.

No other significant mulrivariate results were obtained and, hence, univariate significant findings were not probed.

Thus, the well siblings of children with chronic medical conditions were described by their parents as having significantly more behavior problems at both points in time on the BPC subscales examined as a set and displaying significantly more shy-anxious behavior than siblings of children who were not afflicted with chronic disorders. Neither age nor sex of the siblings qualified this relationship.

Summary of Hypothesis 1

The results of the three separate multivariate analyses of variance provided partial support for the hypothesis that siblings of children with chronic illnesses would have significantly more emotional and behavioral adjustment problems at both points in time than siblings of children not afflicted with chronic illnesses. That siblings of chronically ill children have more behavioral adjustment problems, especially those of a shy-anxious nature, was clearly demonstrated. Likewise, it was found that the passage of time did not seem to affect the degree of behavioral problems reported. Similarly, the time factor had little effect on the self-concept aspect of emotional adjustment. Siblings of chronically ill children reported comparable levels of self-esteem to siblings of non ill children at both points in time. Where the passage of time seemed to make a difference was on the anxiety measure, particularly on the WO subscale of this measure. The WO scores of children in the two groups decreased significantly at the time of the second interview, though considerably more for the control group. Furthermore, when analyzed as

a set, the anxiety scores of males and females within the index group differed significantly from the anxiety scores reported by male and female control group siblings at each point in time. This suggested that the anxiety level of siblings with chronically ill brothers and sisters was different from that of siblings without ill brothers or sisters at both time periods. Finally, age emerged as a factor which had some impact on emotional adjustment but not on behavioral adjustment. Older children in both groups, i.e. those in grades 7 to 12, rated themselves as having lower levels of self-esteem especially in the family context and at a general level than younger children, i.e., those in kindergarten to grade six. On the other hand, the older children in both groups received lower defensiveness scores than the younger children suggesting more honest and less socially desirable responding on their part.

Between Group Differences - The Families

Hypothesis 2

Hypothesis 2 stated that families in which there was a chronically ill child would report lower levels of family functioning at both points in time than families in which there were no chronically ill children. Again, due to the fact that Family Functioning Index (FFI) scores were available for both mothers and fathers in each group and at each point in time, correlated t-tests were undertaken to determine whether there were any significant differences between the FFI scores of parents within each group at either data point. Employing the Bonferroni adjustment procedure so as not to inflate the error rate, no significant differences

were found in parents' ratings ($p > .025$). On this basis, mother's FFI score and father's FFI score for each family in the study were combined to form a single score for Time 1 and a single score for Time 2. All subsequent analyses were carried out using these combined scores.

The mean FFI scores of index and control families are shown in Table 18. Examining the means it is apparent that families in which there was a chronically ill child had the lowest scores on this measure at both points in time, in line with the investigator's prediction. It is also evident that the FFI scores in both groups are lower at the second data point than at the first.

Despite the suggestion of group differences by visual examination of the means, the results of the analysis of variance performed on FFI scores do not uphold the predicted relationship between group belonging and family functioning, $F(1, 50)$, $p = .159$. A significant Time effect was found however, $F(1, 50) = 4.23$, $p = .05$. This effect is pictorially depicted in Figure 1 where it can be seen that FFI scores decreased at Time 2 in both groups. It also appears that the decline was greater for the index group, but the Group x Time interaction did not statistically validate this.

Impact of Moderator Variables on the Adjustment of Siblings of Chronically Ill Children

Hypothesis 3

According to the third hypothesis, siblings of children with chronic illnesses marked by periods of remissions and exacerbations (JRA, Gastrointestinal disorders) would have significantly more emotional

Table 18

Mean Family Functioning Index Combined Scores of Parents in Index and Control Groups

	Group	
	Index[a]	Control[b]
FFI combined score		
Time 1	52.56	54.48
Time 2	50.52	53.89

Note. [a] $\underline{n} = 25$

[b] $\underline{n} = 27$

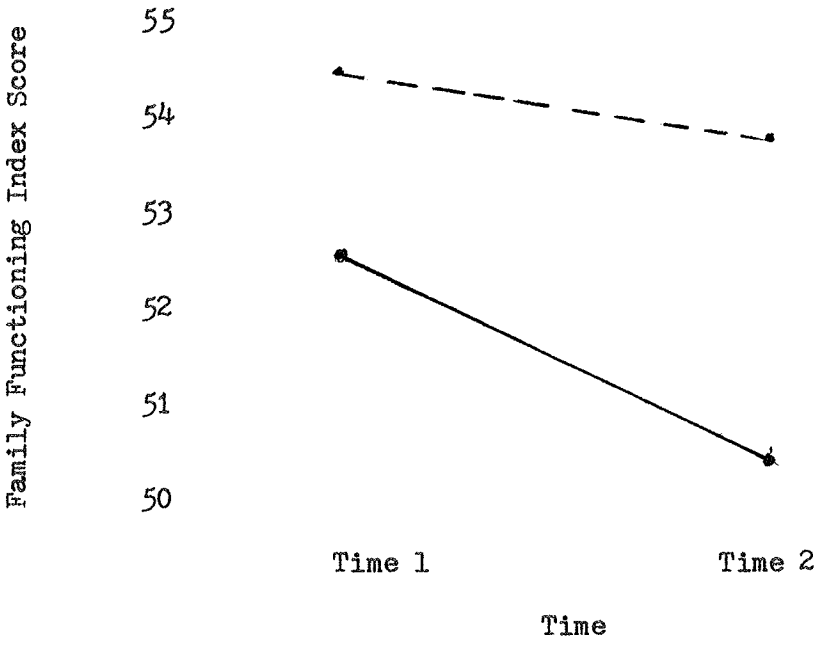


Figure 1. Changes in Family Functioning Scores of Index and Control Families Over Time.

Note. _____ Index

-------- Control

and behavioral adjustment problems at both points in time than siblings of children with chronic illness not characterized by remissions and exacerbations (Diabetes). Table 19 contains the results of the multivariate analysis of variance conducted for each dependent measure when subjects in the index group were classified according to the stability of prognosis of their brothers'/sisters' illness.

As can be seen, contrary to prediction, there were no significant differences at either point in time between siblings of children whose condition was marked by periods of remission and exacerbation and siblings whose sisters/brothers had more stable prognoses. In contrast to the statistical results, however, there was some support for this hypothesis in the semi-structured interview. This will be discussed in the section describing the findings from the interview.

Hypothesis 4

The fourth hypothesis pertained to the amount of time parents spent daily in treatment-related activities with or for their chronically ill child. It was expected that the greater the amount of parents' time required for daily management of the ill child, the more emotional and behavioral problems siblings would experience at both points in time. This hypothesis was investigated via canonical correlation and pearson correlation analyses. Unfortunately, the results of the canonical correlation procedure with the sample size available in this study (Index: N = 27) and more than two criterion variables are not very reliable and should not be interpreted. Furthermore, though somewhat more reliable and valid, the results of the pearson correlations must be interpreted with caution because of the small size of the sample (Lind, Note 8).

Table 19

Summary of the Multivariate Analyses of Variance: Siblings of Children with a Stable vs an Unstable Prognosis

SOURCE	MS	df	F	p≤
Group				
SAI-Multivariate T		4, 21	.15	
General	.00	1, 24	.06	
Peer	.00	1, 24	.00	
School	.00	1, 24	.07	
Family	.00	1, 24	.10	
WITF-Multivariate T		4, 21	.23	
Physiological	.08	1, 24	.01	
Worry-Oversensitivity	.66	1, 24	.05	
Fear-Concentration	.38	1, 24	.03	
Defense-Lie	14.89	1, 24	.92	
BPC-Multivariate T		3, 21	1.08	
Personality-Problem	22.22	1, 23	.36	
Conduct-Problem	121.94	1, 23	1.49	
Inadequacy-Immaturity	23.12	1, 23	2.53	
Time				
SAI-Multivariate T		4, 21	.62	
General	.00	1, 24	.06	
Peer	.00	1, 24	.47	
School	.00	1, 24	.18	
Family	.00	1, 24	1.25	
WITF-Multivariate T		4, 21	3.84	.05
Physiological	.02	1, 24	.01	
Worry-Oversensitivity	6.23	1, 24	1.36	
Fear-Concentration	4.92	1, 24	2.51	
Defense-Lie	2.33	1, 24	.92	
BPC-Multivariate T		3, 21	2.39	
Personality-Problem	.08	1, 23	.01	
Conduct-Problem	40.50	1, 23	4.91	
Inadequacy-Immaturity	2.88	1, 23	3.17	

Table 19 (Con't)

SOURCE	MS	df	F	p≤
Group x Time				
SAI-Multivariate T		4, 21	.65	
General	.01	1, 24	1.04	
Peer	.03	1, 24	1.92	
School	.00	1, 24	.03	
Family	.01	1, 24	1.21	
WITF-Multivariate T		4, 21	1.41	
Physiological	4.71	1, 24	3.16	
Worry-Oversensitivity	8.00	1, 24	1.75	
Fear-Concentration	12.00	1, 24	6.12	
Defense-Lie	3.72	1, 24	1.48	
BPC-Multivariate T		3, 21	.17	
Personality-Problem	.05	1, 23	.01	
Conduct-Problem	1.25	1, 23	.15	
Inadequacy-Immaturity	.25	1, 23	.27	

The amount of time invested daily by parents was analyzed separately for mothers and fathers. It was found that the mothers and fathers of chronically ill children in this sample reported spending quite different amounts of time in treatment/management-related activities with or for their chronically ill child. Not surprisingly, the average amount of time spent daily by mothers exceeded that spent by fathers ($\bar{X}$ mothers = 44 minutes; $\bar{X}$ fathers = 14 minutes) and employment status had an effect on time spent daily by mothers (r = .43, p = .016). Mothers who worked outside of the home tended to spend less time in treatment/management dictated tasks than mothers who were in the home full time. Furthermore, there was a very strong and significant positive correlation between the amount of time spent in treatment/management tasks by fathers and mothers within each family (r = .64, p = .000).

Table 20 contains the correlations between siblings' scores on the dependent measures at the two data collection points and the amount of time reported by each parent that was spent in treatment/management-related activities. Due to the large number of correlations performed, it was possible that several significant correlations could have emerged by chance alone. Therefore, it was decided *a priori* that only relatively large correlations, those which were stable over time, or those that showed a particular pattern related to the temporal dimension would be interpreted.

As can be seen in Table 20, the amount of time spent in treatment/management-related activities by mother had a moderate to strong positive relationship at both points in time with all three clinical subscales of the WITF. This was especially true for the WO subscale and suggested that the anxiety levels of siblings of chronically ill children increased

Table 20

Correlations Between Siblings' Scores on Dependent Measures and Time Spent Daily by Parents in Treatment-Related Activities

	Mother		Father	
Dependent Measure	Time 1	Time 2	Time 1	Time 2
SAI				
General	-.40*	.05	.02	.24
Peer	-.40*	-.32	-.16	-.14
School	.08	-.19	.29	-.26
Family	-.42*	-.12	-.01	.21
WITF				
Physiological	.43*	.33	.20	.26
Worry-Oversensitivity	.50*	.42*	.25	.24
Fear-Concentration	.35*	.34*	.25	.25
Defense-Lie	.01	-.27	.35*	.02
BPC				
Personality-Problem	.00	-.02	.09	.07
Conduct-Problem	.09	.22	.04	.24
Inadequacy-Immaturity	-.07	-.15	.05	-.14

Note. N = 25

*$p < .05$

when mothers spent more time with their ill child and decreased when mothers spent less time with their ill child. There was also some indication of an inverse relationship between time spent by mothers in treatment/management related activities and the Peer subscale of the SAI. That is, there was a trend for siblings' self-concept with regards to peer relationships to decrease as mothers spent greater amounts of time with the ill child and to increase when mothers invested lesser amounts of time with the ill child. None of the other SAI subscale correlations were stable over time. Interestingly, however, the data suggests that the passage of time with respect to this moderating variable may have had an effect on siblings' self-concept. At the first data point there was a moderately strong negative relationship between all of the SAI subscales, except the School subscale, and the treatment/management variable with regards to mother. At Time 2, however, there was no such evidence except on the Peer subscale. No evidence of a relationship between this moderator variable and the BPC subscales was observed.

There was also no evidence to suggest a relationship between fathers' involvement in daily treatment/management of the chronically ill child and sibling adjustment at either point in time. The only significant correlation was moderately sized and occurred with the WITF DL subscale at Time 1. It seems likely that this was a spurious finding.

In summary, the fourth hypothesis was partially validated. Greater amounts of time spent by mothers in treatment/management-related activities with or for the chronically ill child correlated with poorer emotional adjustment of the well siblings in the family. This was not the case for the behavioral adjustment of siblings, however. Time spent by father in treatment/management-related activities with the ill child had

no relationship to the psychosocial adjustment of the well siblings in the family.

Hypothesis 5

The fifth hypothesis stated that siblings from families with low levels of family functioning would have significantly more emotional and behavioral adjustment problems at both points in time than siblings from families with high levels of family functioning. In order to test this hypothesis, families within the index sample were divided into high and low functioning groups on the basis of the combined FFI scores of mothers and fathers. Due to the earlier reported finding of a significant decrease in FFI scores at Time 2, high and low functioning groups were formed for each data collection point separately. This was a natural division resulting from the spread and frequency of scores. Those whose FFI scores fell above the midpoint of the distribution at Time 1 constituted the high functioning group, while those whose scores fell at or below the midpoint of the distribution composed the low functioning group. Each group consisted of the same number of families.

The results of the multivariate analyses of variance performed on each dependent measure at each data point are presented in Table 21. They indicate that siblings from high and low functioning families did not differ significantly from each other on the WITF or SAI subscales at either data collection point. There was, however, a significant group main effect at Time 1 when the BPC subscales were examined as a set, F (3, 23) = 3.53, p = .031. Further inspection revealed that of the univariate scales the CP subscale at Time 1 was significant using the Bonferroni adjustment, F (1, 25) = 5.85, p = .02. As can be seen in Table 22

Table 21

Summary of the Multivariate Analysis of Variance on SAI, WITF, and BPC Scores of Index Siblings from High and Low Functioning Families at Individual Points in Time

	FFI Time 1[a]				FFI Time 2[b]			
MEASURE	MS	df	F	p≤	MS	df	F	p≤
SAI								
Multivariate T		4, 22	.30			4, 21	.56	
General	.01	1, 25	.66		.00	1, 24	.14	
Peer	.00	1, 25	.09		.00	1, 24	.00	
School	.00	1, 25	.02		.00	1, 24	.24	
Family	.04	1, 25	1.10		.04	1, 24	1.79	
WITF								
Multivariate T		4, 22	.77			4, 21	1.29	
Physiological	12.32	1, 25	2.89		2.20	1, 24	.39	
Worry-Oversensitivity	.62	1, 25	.07		13.85	1, 24	1.56	
Fear-Concentration	8.30	1, 25	1.48		1.06	1, 24	.13	
Defense-Lie	.34	1, 25	.03		.06	1, 24	.01	
BPC								
Multivariate T		3, 23	3.53	.05		3, 21	.96	
Personality-Problem	11.33	1, 25	.35		4.81	1, 23	.13	
Conduct-Problem	319.50	1, 25	5.85	.017	73.94	1, 23	1.86	
Inadequacy-Immaturity	1.69	1, 25	.27		.64	1, 23	.12	

Note. [a] $n = 27$

[b] $n = 25$

Table 22

Mean Behavior Problem Checklist Scores of Index Siblings from High and Low Functioning Families at Each Point in Time

		Level of Family Functioning	
Subscale	Time	Low	High
Personality-Problem	1	9.15	7.86
	2	7.58	8.30
Conduct-Problem	1	14.38	7.50
	2	10.42	5.69
Inadequacy-Immaturity	1	3.00	2.50
	2	1.83	2.15

which gives the mean scores of the two groups at each data point on the three subscales of the BPC, siblings from low functioning families had slightly higher PP and II ratings at Time 1 but not at Time 2 than those from high functioning families. Most remarkably though, they were rated by their parents as engaging in almost twice as much anti-social behavior as siblings from families with higher levels of functioning. This table also reveals that within the high functioning group, well siblings were rated as engaging in more behaviors indicative of personality-problems than conduct-disorders or inadequacy-immaturity. In sharp contrast, within the low functioning group, parents perceived their well children as manifesting more behaviors of an anti-social nature than of a withdrawn or immature nature.

In summary, the predicted relationship between level of family functioning and sibling adjustment received some support. Though no significant differences in emotional adjustment were evident at either point in time when index families were divided into high and low functioning groups, more behavioral maladjustment was reported at the first data collection point for siblings from low functioning families. Examination of the pattern of scores within groups was also revealing. It indicated that at both time periods whereas siblings in low functioning families were clearly defined by their incidence of anti-social behaviors, those in high functioning families were perceived as engaging in similar frequencies of anti-social and withdrawn behavior or a higher incidence of withdrawn behavior.

Hypothesis 6

The sixth hypothesis proposed a relationship between age of the

well siblings in the index group and psychosocial adjustment. It predicted that the older the siblings of chronically ill children, the more emotional and behavioral problems they would have at both points in time. Inspection of Tables 5 and 9 reveal that a significant main effect for Age was found for the set of SAI subscales as well as the set of WITF subscales. Post-hoc analyses indicated that older siblings, i.e., those in grades 7 to 12, had lower self-concept scores in the family context as well as in general, and that they were less defensive than younger siblings, i.e., those in kindergarten to grade 6. However, these findings were not specific to the index sample. Older siblings in both groups rated themselves as having lower self-concept and being more honest. No Age x Group interactions were found to suggest a differential impact of the age variable in terms of group membership.

Therefore, on the basis of the data presented above, it does not appear that there was support for the hypothesis that age acts to moderate the emotional or behavioral adjustment made by siblings of chronically ill children.

Hypothesis 7

According to the seventh hypothesis, female siblings of chronically ill children would have significantly more emotional and behavioral adjustment problems than male siblings of chronically ill children. Validation of this specific hypothesis was not obtained for any of the dependent measures as is evident by the nonsignificant main effects for Sex or interactions of Sex x Group in Tables 5, 6, 9, 10, 15 and 16.

Nevertheless, some support for considering gender as a relevant variable in terms of the adjustment of siblings of chronically ill children

was apparent. The significant Sex x Group x Time interaction which emerged on the WITF subscales as a set indicated differences in the degree of anxiety expressed by males as opposed to females in the index group when compared to males and females in the control group at each point in time. The precise nature of these differences was not evident however, as none of the subscales of the WITF was univariate significant.

Additional Between Group Differences

In the course of the study, parents in both the index and control groups were asked questions directed at attaining an estimate of the amount of leisure time they spent daily with their well children and information regarding whether any changes had occurred for the family and/or individual members of the family unit in between the two scheduled appointments.

The mean number of minutes parents in each group reported spending in leisure activities with the well sibling who participated in the study is presented in Table 23. Reference to this table indicates that both mothers and fathers in the control group independently estimated spending more time engaging in leisure activities with their well children than mothers and fathers in the index group. The difference between fathers in the two groups was significant, F (1, 45) = 5.72, p = .021, while that between mothers was not, F (1, 45) = 3.01, p = .09.

The data with respect to the question of whether any significant changes or events had occurred in the family between the two scheduled appointments appears in Table 24. Examination of this table reveals that more than twice as many index families than control families (17 vs 7)

Table 23

Mean Time Spent by Parents in Daily Leisure Activities With Their Well Children

	Group	
	Index	Control
Mother	53	76
Father	35	61

Note. N= 27 in each group.
Numbers reported are in minutes.

Table 24

Frequency of Reported Changes between the First and Second Interviews

	Group	
	Index %	Control %
Change(s)	65.4	25.9
No change(s)	34.6	74.1

Note. N = 27 in each group.

acknowledged experiencing remarkable changes in between the two interviews. Of these 17 index families, 10 (59%) identified changes which were directly related to their ill child's medical condition. In some cases the changes were perceived as making things easier for the family (44%); in other cases they were described as making things harder for the family (12%); while in many cases the changes were viewed as making things both easier and harder for the family (44%).

Finally, the relevance of family functioning as a moderator variable of sibling adjustment in both groups was probed via canonical correlation and both similarities and differences were found. In both groups, the correlation between the set of FFI scores (Time 1, Time 2) and the set of SAI subscales was nonsignificant (Control: $\underline{R} = .49$, eigenvalue = .24, $\underline{p} = .10$; Index $\underline{R} = .69$, eigenvalue = .47, $\underline{p} = .31$) and, hence, follow-up via inspection of the individual canonical variates was not undertaken. Furthermore, in both groups a significant canonical correlation between the set of FFI scores and the set of WITF subscales was found (Control: $\underline{R} = .58$, eigenvalue = .34, $\underline{p} = .01$; Index: $\underline{R} = .87$, eigenvalue = .76, $\underline{p} = .007$). However, whereas the WO subscale by itself seemed to contribute the most of all the subscales in the predictor set to the significant correlation in the control group ($sdw_1 = .64$; $sdw_2 = -.93$), within the index group the DL subscale also emerged as making a relatively large contribution to the significant correlation between the set of WITF subscales and the set of FFI scores ($WO_1 sdw = 1.47$; $WO_2 sdw = -1.24$; $DL_1 sdw = .96$; $DL_2 sdw = .63$). When the relationship between the set of FFI scores and the set of BPC subscales was analyzed, another difference between the index and control groups was identified. The canonical correlation for the two sets of variables was not significant for the control

group (R = .52, eigenvalue = .27, p = .07), but was significant for the index group (R = .83, eigenvalue = .69, p = .04). While all of the BPC subscales emerged as having fairly large standardized weights, the CP subscale at Time 2 (sdw = -1.52) made the largest contribution of all the subscales to the significant canonical correlation. Thus, in summary, whereas the WO subscale of the WITF seemed to have a strong connection to FFI scores for both groups, the DL subscale of the WITF and the CP subscale of the BPC seemed to be connected to FFI scores only within the index group.

Additional Findings Pertaining to the Index Group

Families in the index group were asked a number of questions over the course of the two interviews they participated in which were not asked of control group families. Most of these questions were related to the chronic illness dimension, i.e., the differentiating factor between the two groups. They included information regarding affiliation with support groups, satisfaction with current levels of support, and feelings about the adequacy or inadequacy of time spent with the well children in the family. Table 25 contains a summary of the data collected with respect to each of these questions.

What is most surprising about this data is that only 25.9% of the families reported belonging to a support group, yet 60% stated that they would like more support. Also worthy of note is the fact that a sizeable proportion of both mothers and fathers (39.2% and 56.2%, respectively) alleged that they did not feel that they spent a sufficient amount of time with their well children. In many cases, parents cited the time

Table 25

Summary of Responses to Questions Specific to the Index Group

	Yes	No
Affiliation with a support group[a]	7 (25.9%)	20 (74.1%)
Desire for increased support[b]	15 (60%)	10 (40%)
Sufficient time spent with well sibling - Mother[c]	14 (60.8%)	9 (39.2%)
Sufficient time spent with well sibling - Father[d]	7 (43.8%)	9 (56.2%)

---

[a] N = 27

[b] N = 25

[c] N = 23

[d] N = 16

demands of treatment/management related activities with the ill child as an impediment to devoting time to their well children. The moderately sized negative pearson correlation between this variable and time spent in treatment by mothers supports this finding (r = -.45, p = .015). Though in the same direction, the relationship between the variable and time spent in treatment by fathers was weaker and nonsignificant (r = -.21, p = .22).

Semi-Structured Interview

The following section will describe index siblings' responses to the questions asked in the semi-structured interview. Although the semi-structured interview was administered at both Time 1 and Time 2, i.e., on a longitudinal basis, in most cases the data it elicited was quite consistent over time. Therefore, unless there were blatant changes in the replies given at the second interview, no distinction between Time 1 and Time 2 will be made below. Only the most interesting and dramatic results will be elaborated upon. These findings can only be viewed as interesting trends in light of the size of the index group and the problems associated with a potentially unrepresentative sample.

Knowledge of Chronic Illness

The majority of siblings interviewed (89%) had some information about their chronically ill sister's/brother's medical condition. There were no remarkable differences amongst the three illness groups. However,

the amount and adequacy of siblings' knowledge showed much variability from one family to another. Though age seemed to play a moderating role in this regard, some relatively young siblings did demonstrate a sophisticated understanding of the illness and its implications, while other older siblings appeared to have only a limited and very superficial comprehension of the disease and its implications. Two 9 year olds and one 5 year old (11%) alleged that they knew nothing about their brother's/sister's condition. The latter received an explanation from her parents in between the two interviews but this did not seem to have occurred for the former.

Two of the most interesting responses to the questions probing siblings' understanding of the chronic illness came from a $13\frac{1}{2}$-year-old female and a $15\frac{1}{2}$-year-old female. Though the former had some knowledge of her ill sibling's condition, she spontaneously asserted that "they never tell me anything. I remain kind of clued out", suggesting that she wanted to be more informed. On the other hand, the $15\frac{1}{2}$-year-old confessed knowing very little and did not seem to want more information. She said, "He gets tested to see if he's getting better." When asked if her brother was improving, she stated that "as far as I know. I don't ask."

Perceptions of Impact of the Illness on the Afflicted Child

Had their brother/sister changed with the disease? Sixty-three per cent of the well siblings said "Yes" and 37% said "No". This rate of response was quite uniform across the three illness groups represented in the study. The majority of responses given to this question indicated

negative effects the disease had on the ill child, especially increased irritability. Nevertheless, some well siblings were able to identify positive changes in their ill sister/brother emanating from the illness experience, e.g., increased responsibility, while others gave more neutral responses related to restrictions the illness imposed in the ill child's daily life, e.g., dietary regulations for children with Diabetes. Table 26 contains a sampling of the answers given to this question.

To some degree age seemed to operate as an intervening variable. Younger children tended to focus on changes which they perceived had negative repercussions for themselves. For instance, one $9\frac{1}{2}$-year-old said, "She doesn't want to play any of my games anymore. She likes to read books now all the time." Another sibling of the same age, in a very emotional tone of voice, declared that "before she used to be simple. She didn't need much things. Now she needs more attention from the family." Older siblings, in contrast, appeared aware of more of a mixture of positive and negative effects on the ill child and were less egocentric in their replies. Their answers also tended to be less emotionally based and more intellectualized. An example is the statement of a 14 year old sibling who claimed that "he's a little bit more responsible and he tends to blame things on it. Like he might say that 'I have a bad temper because I had a bad needle this morning'."

Effects on the Family

Despite the fact that 62% of the index sample denied that their brother's/sister's illness had caused their family any problems, there were noticeable differences amongst the three illness groups. Whereas

Table 26

Examples of Responses Given by Well Siblings to the Question of Whether their Brother/Sister Had Changed with the Chronic Illness

Changes	Responses
Negative	"He's got a bad temper and he gets spoiled. He makes me feel bad for eating candy in front of him."
	"He's impatient and doesn't think of anyone else but himself . . ."
	"Whenever I want to do something she gets mad that she can't do it and, she doesn't like to be with other people much."
	"It's different living with her now . . . she's very short-tempered and harder to get along with."
	"Little things that wouldn't bother other people bother her."
	"She was running around more and more happier before."
Positive	"She's more responsible. It gave her some self-respect."
	"She's more assertive - not easily intimidated."
Neutral	"Not his personality or friends, just his eating habits and routines."

the large majority (78%) of the siblings of children with JRA did not report any family problems as a result of the illness, approximately half of the siblings of children with Diabetes (46%) and Gastrointestinal disorders (50%) did contend that there were family problems as a consequence of the chronic illness of their sister/brother. Within the Diabetes subgroup, daily meals and snacks, birthday parties, Hallowe'en, and other holidays where food is of central importance were labelled as being affected for all family members by the dietary restrictions of the ill child. An impact on vacations was also commented upon, related to the need to have an adequate supply of insulin, needles, etcetera on hand and to be close to a hospital. The issue of the cost of medical services and supplies, e.g., insulin, was also raised by a few of the siblings of Diabetic children. Within the Gastrointestinal disorders subgroup, increased worry and concern (anxiety) was the major family problem identified.

Interestingly, though most siblings of children with JRA did not feel that family problems had been created by the illness existent in the family, this subgroup's response to a more specific question about parental worrying ("Do you think that your parents often worry about (ill child's) health?") was very consistent with the response of siblings from the other two illness groups. Of the 26 siblings who answered this question, 24 (92%) answered affirmatively. Table 27 provides some examples of responses given by well siblings to this question. From inspection of the table, it is evident that many siblings, regardless of age, sensed a great deal of worry and concern on the part of their parents with respect to the chronically ill child in the family. None of the answers provided were superficial. Rather, it seemed apparent that

Table 27

Examples of Responses to a Question Regarding Parental Worry about the Chronically Ill Child's Health

"If he gets sick, my mom thinks he's going to die sometimes."

"My mom worries about my sister's lifespan, going blind, susceptibility to disease. . ."

"How his friends will react to him when he's older . . . that he'll be left out in physical activities."

"My parents are always concerned."

"Definitely. Whether he's testing; if he's having enough insulin; if he carries a little sugar with him all the time in case of reactions. About when he's out with his friends; about his diet; if he's not home when he said he would be, they worry that he's had a reaction."

"They worry about losing her and kids teasing her at school. They worry that I'm too rough when we play. She could hit me but I can't hit her back."

"My mother tries to stay home a lot and be with her all the time. She just worries about her all the time."

"If he's ever going to get better."

"About whether it's going to get worse."

"They worry about people not getting along with her and that she doesn't talk about it much. They worry when she goes to camp."

"About his emotional well-being. They don't want him worrying about things."

"Mom and dad worry a lot about her. They don't want her unnecessarily upset over anything and are constantly warning her not to eat certain things. If she does get sick, say with a cold, mom instantly insists that she goes to the doctor."

siblings had given this issue much consideration and were very aware of their parents' reactions to the ill child.

With reference to the question of who in the family was most responsible for the care of the ill child, mothers were the most popular choice when looking at the entire sample. Seventy-three per cent of the sibling group contended that their mothers were most involved in the care of their ill brother/sister. However, some differences emerged between the illness subgroups. In sharp contrast to the Diabetes and JRA subgroups where both parents were attributed with equal involvement in only 10% of the cases and mothers were viewed as most involved 80% of the time, 60% of the siblings in the Gastrointestinal disorders subgroup declared that their mothers and fathers shared the responsibilities of looking after the child afflicted with the chronic illness and identified mothers alone 40% of the time. In elaborating upon their responses to this question, several siblings made remarks which suggested that they did not feel favorably about their mother's or parents' degree of involvement with their ill sister/brother. Again, age did not seem relevant in this regard. For instance, one 17 year old female sibling commented that "mother lifts anything heavy for her so she won't have to. She refuses to let her carry a grocery bag. It usually is given to me. . .", and a 16 year old male sibling said, "Mom thinks for her. She takes all the responsibility." Similarly, a 10 year old girl stated that "she (Mom) gets him everything he wants. She takes him swimming and I go by myself."

In line with the finding that mothers of children with Diabetes and JRA were seen by their well children as assuming the major role in the care of the ill child, mothers from these two illness groups were also perceived by their healthy children as having given up the most due to

their child's medical condition. Mothers were mentioned in this context by 82% of the siblings in the former illness subgroup and by 100% of the siblings in the JRA subgroup. In the Gastrointestinal disorders subgroup, mothers were viewed as giving up the most of all family members by 67% of the siblings. In contrast to the previously reported observations by siblings that fathers of Diabetic children and of those with JRA had similarly limited degrees of involvement in the care of the ill child, differences between fathers in these two illness groups emerged with respect to the question of who in the family had given up the most due to the ill child's condition. Fathers of Diabetic children were seen by 44% of the siblings as having given up the most in the family or were referred to along with mothers, whereas fathers of children with JRA were never mentioned in this regard. However, consistent with the results of the previous question, the fathers of children with Gastrointestinal disorders were referred to either alone or together with mothers by 50% of the siblings.

The reasons provided as a rationale for choosing one parent or another or for mentioning both parents were similar in all three groups and related to both the physical (treatment) and emotional demands of the chronic illness. One sibling, for example, offered the following explanation: "She (mom) had a job and she quit it. I think it's because she wants to keep an eye on (ill child)." Another sibling stated that, "it's always on her (mom's) mind. She has no piece of mind. She carries around (ill child's) illness all the time." Still another well sibling postulated that "he (dad) takes her to her appointments pretty regularly and I think he takes things harder than mom. He keeps it all inside too."

Of all the family members, who did well siblings think was most disturbed or unhappy because of the chronic illness? Table 28 presents a breakdown of the responses given to this question. It can be seen that siblings chose themselves more often than any other family members. One-third of all the siblings who participated in the study pointed to themselves as suffering most or being most upset because of their brother's/sister's chronic medical condition. Looking at each illness subgroup individually, it is also apparent that the siblings of children with JRA gave this response most frequently. Four of the ten siblings in this subgroup identified themselves as most unhappy in relation to the chronic illness factor. They justified their answers with comments such as: "nobody tells me about this stuff"; "she can't do as many things with me as I'd like her to. I always feel sorry for her. I don't want to do thinks she can't do"; and, "sometimes I feel a little left out." One sibling would not or could not elaborate on her response but, at both interviews, selected herself as being the most unhappy of all family members. Siblings of children with Diabetes were next most likely to point to themselves in response to this question, followed by siblings of children with Gastrointestinal problems.

Averaging across the illness subgroups, mothers and fathers were identified with the same frequency, i.e., 22% of the siblings referred to their mothers and 22% referred to their fathers as being the family member most upset by the chronic illness. A remarkable difference between illness subgroups in terms of whether fathers, as opposed to mothers, were pinpointed, was found, however. Whereas 40% and 33% of the siblings of children with JRA and Gastrointestinal disorders respectively chose their mothers, fathers were never selected by siblings in either subgroup as

Table 28

Family Members Identified by Well Siblings as Being Most Unhappy

		Illness Group		
Family Member	Index Group %	Diabetes %	JRA %	Gastrointestinal %
Me	33	27	40	17
Mom	22	18	40	33
Dad	22	36	0	0
Other (Combinations)	23	19	20	50

being most emotionally burdened by the chronically ill child's medical status. In contrast, siblings of the children with Diabetes saw their fathers as being most upset twice as often as their mothers. This finding may relate to the course of the illness and, thus, support the third hypothesis. More explicitly, Diabetes is not marked by periods of remission and exacerbation but the other two illnesses do have these characteristics.

The final question asked pertaining to well siblings' perceptions of family functioning probed whether any member of the family had extra chores and/or responsibilities because of the chronically ill child's condition. It was asked in an attempt to determine whether well siblings felt there was an unequal division of labor in the family related to the ill child's chronic medical condition. Although almost half of the index sample acknowledged that family members did have more chores and/or responsibilities (48%), examination of the rate of this response for each illness subgroup revealed that siblings of children with Diabetes stood out as different from the other two illness subgroups. While 64% of the well siblings of Diabetic children claimed that they had to help out more at home due to their brother's/sister's chronic illness, only 20% and 30% of the siblings of children with JRA and Gastrointestinal problems, respectively, reported this. Again, this discrepancy suggested support for Hypothesis 3, i.e., that the differentiating feature between these illness subgroups (presence or absence of remissions and exacerbations) played a role in this finding.

What sorts of extra tasks did well siblings engage in? A sample of some of the responses provided by well siblings is presented in Table 29. Regardless of illness subgroup or age of the well sibling, similar types of demands seem to have been placed on them by their parents. These

Table 29

Extra Chores and Responsibilities Assumed by Well Siblings
Because of their Brother's/Sister's Chronic Medical Condition

Illness Group	Response
Diabetes	"I do her testing when she's sick."
	"I make his bed, go to the store for him, take out the garbage. He doesn't take out the garbage."
	"If she's tired we do the jobs. Or, if she's testing herself, we clean up for her."
	"He's gotten away with it up until now. Mom always calls me for help. They ask me to shovel steps when he's perfectly able to."
	"When mom's not home, I have to cook for him. He could do it but dad makes me do it."
	"She gets to play and mom calls me to do stuff."
JRA	"I do all her chores, when she's sick. . ."
	"We share a paper route. I do more because she has less stamina."
	"We have to help her with her exercises and her walking. She doesn't want to do things for herself."
Gastro-intestinal	"When he was really sick, we had to bring him things. We were like servants. We also had to be quiet when he's sleeping."
	"Dry dishes, fix meals, clean up . . . . With all the pressure of school and home, I thought I was going to have a nervous breakdown. Instead I got sick for about one week. My doctor told me I was over tired . . ."

included increased domestic activities and direct assistance to the ill child with treatment-dictated activities. Also worthy of note is that the majority of healthy siblings indicated that they resented these extra demands.

In summary, the well siblings of chronically ill children who participated in this study perceived a number of effects on the family directly related to their sister's/brother's chronic medical disorder. Siblings rank ordered themselves first from amongst all family members as being most unhappy as a result of their brother's/sister's illness. Most siblings believed that their parents were frequently worried about the ill child and, sometimes, unnecessarily so. A tone of resentment and of inequality was sensed in the response of many of the well siblings to the questions regarding effects on the family. Some interesting differences amongst the illness subgroups also emerged. Most remarkably, siblings of children with Gastrointestinal disorders more frequently saw both of their parents as involved in the care of their ill brother/sister as well as both of their parents as having to sacrifice the most for the ill child in the family. In contrast, siblings of children with JRA and Diabetes were more likely to identify their mothers alone in these two respects. Furthermore, some validation for the third hypothesis which pertained to whether or not the illness was defined by periods of remission and exacerbation was found.

Impact on Well Siblings

In response to the question of whether well siblings felt that their ill sister/brother received "special treatment", 46% of the index sample

said "Yes", 27% said "No", and 27% changed their answers at the second interview. Individual illness group differences were observed in this regard. Almost three-quarters of the siblings of Diabetic children (73%) answered affirmatively to this question. The remainder (27%) replied negatively. No discrepancies in responses over time were revealed. However, in both the JRA and Gastrointestinal disorders subgroups, much inconsistency in the responses provided by siblings at Time 1 and Time 2 was noted. One-third of the JRA subgroup (33%) and two-thirds of the Gastrointestinal subgroup (67%) offered different replies to this question at the two interviews. The role of the distinguishing feature amongst these three illnesses (the presence or absence of exacerbations and remissions) must again be pondered, in light of these findings.

As is evident in Table 30 which provides some verbatim responses of well siblings of all ages to this question, special treatment in the form of the purchase of material objects for the ill child as well as the provision of more attention to the sick child were identified. A trend for younger siblings to articulate responses indicative of material inequality and for older siblings to identify more inequality in the emotional arena was found. The responses of siblings from the JRA and Gastrointestinal groups also reveal the noted inconsistency between replies at the time of the first and second interviews.

When asked whether they ever felt jealous of their chronically ill brother/sister, 39% of the index sample declared that they did, 50% denied this, and 11% gave different answers at the two interviews. Not surprisingly, 64% of the well siblings of children with Diabetes confessed feelings of jealousy and no changes in responses occurred over time. Likewise, the findings that 50% of the well siblings of children with Gastrointestinal disorders offered different replies at the two interviews and

Table 30

Responses of Well Siblings to the Question of Whether Their Ill Sister/Brother Receives 'Special' Treatment

Illness Group	Response
Diabetes	"She doesn't have as many chores as me. . . When she has to go to the hospital, she gets to do a lot of things we don't. And when she's in the hospital, my mom only comes home once in a while."
	"He gets more things--candy, toys, models, money."
	"She gets away with more at times. Mom feels sorry for her."
	". . . not really material items, but other things. . . He's never had a spanking. My other brother and I have. He gets a little more attention."
	"Very often. Material wise, she can get things faster. Attention wise, my parents are paranoid. If she gets upset, they think it's related to her Diabetes."
	"They just worry about him more. . . Other people tend to worry about him too. . . ."
JRA	"Sometimes. . . It doesn't bother me except when her class sent her a big box of gifts. . . She used to but not anymore."
	"She doesn't get more material things, but she seems to get cared about more. She gets more attention. They listen to her more."
	"For bad behavior her punishment is much less severe than mine. Mom and dad don't always stick to what they say for her punishment."
	"People give her presents more often. . . It just doesn't seem fair. I feel kind of left out."
Gastro-intestinal	"They're very concerned about him. They're more careful with him and, he's spoiled. They're more into what's happening with his life."
	"Not now, but when she was really sick she did get special treatment. Mom and dad bought her a lot of things that I never received. If we went out, it was always to a place she chose. . . special treatment, that used to make me furious."

that the other 50% asserted that they did not feel jealous were not unanticipated. What was unexpected was that only 33% of the well siblings of children with JRA acknowledged feelings of envy, the remainder did not, and there were no discrepant responses over time.

With reference to the question of whether their ill brother/sister was hard to get along with, almost half of the index group (46%) said "Yes" and another 19% said "Sometimes". Thus, the majority of siblings (65%) claimed that they had this experience. The well siblings of children with Gastrointestinal disorders reported difficulty getting along with the ill child most frequently (67% "Yes" and 17% "Sometimes"), followed quite closely by the siblings of children with Diabetes (55% "Yes" and 18% "Sometimes"), and not very closely by the siblings of children with JRA (22% "Yes" and 22% "Sometimes"). As is obvious, the majority of well siblings in the latter group denied encountering problems in getting along with the sick child in the family.

Siblings' global perceptions of whether having a chronically ill sister/brother had affected their life in a negative and/or positive way(s) were also queried. While 29% of the entire index sample declared that there had been no effect on their lives, the siblings of children with Gastrointestinal disorders were most likely to give this response (40%). Siblings from this illness group were also the most likely to provide responses suggestive of the positive effects of this experience (40%). Neither siblings of children with Diabetes or JRA recognized favorable effects only. That is, siblings of Diabetics were most prone to identifying both negative and positive features of the illness experience (64%). For siblings in the JRA subgroup, both negative and positive aspects were delineated in 38% of the cases and only negative effects were identified by 38% of the siblings. Thus, differences amongst

the three illness groups emerged such that the well siblings of children with Gastrointestinal disorders presented themselves as being less affected on the whole by the illness experience than siblings in the other two illness subgroups.

Table 31 contains some examples of the responses given by siblings in each of the three illness subgroups. It can be seen that the content of the negative responses overlaps with the data presented in reply to the questions described above. Siblings mentioned resentment of the special treatment their ill brother/sister was the recipient of, jealousy, dietary restrictions which they felt were imposed on them because of their sister's/brother's medical status, etcetera. It is also apparent that the more positive consequences encompass a changed attitude toward people in general, including increased acceptance of and sensitivity to others, in addition to a closer bond with the ill child and decreased anxiety about medical institutions such as hospitals. A few of the siblings of Diabetic children also pointed out they had become more nutrition and health oriented.

The final question of the semi-structured interview had more of a projective element to it than the other questions and asked siblings what advice, if any, they had for children who recently found out that their brother/sister had the same chronic illness as their own brother/sister. All 27 siblings offered advice and were quite talkative during this portion of the interview. The responses given varied from one sibling to the next but a number of common themes were expressed across all three illness subgroups. A few siblings claimed that they would tell other siblings that the first year is the most difficult, that they should expect to have feelings of exclusion, and that they should not be excessively worried

Table 31

Examples of the Positive and Negative Effects of Living with a Chronically Ill Sister/Brother

Illness Group	Effect: Positive	Effect: Negative
Diabetes	"I've shown her needles and stuff for Show and Tell. Most of the kids were interested."	"I can't have things (food) that I want to."
	"Better understanding of disease."	"I get depressed at times. It makes me sad to think of how it has affected her life."
	"More feeling for people with chronic illness."	"Sometimes it's hard to treat him normally."
	"Learned about hospitals - I'm less afraid of it."	"Mom and dad spend a lot of time with him . . . I don't get as much attention as I would like."
	"I'm more aware of food--what's good for me and what's not."	
JRA	"We're closer now. We do more things together. We don't argue as often."	"Kids in the class used to tease me."
	"I understand other people's problems more."	"My grades went down."
	"I give up things now more easily."	"When I want to go out I can't, because she doesn't want to be alone. Or else, I take her with me."
		"I'm a little unhappy because of it."
		"Kids at school think its catchy so they don't play with me."
Gastro-intestinal	"How to deal better with someone who is sick."	"We have to act differently around the house. He's really hard to get along with."
	"more medical knowledge."	
	"More patience, understanding, determination, and sensitivity."	

about their sister's/brother's medical condition due to currently available sophisticated technology. Some siblings thought it was important for other children to know that often the ill child may take advantage of his/her sickness and that this should not be allowed. Still others advised that the well siblings should be more considerate of their parents because of their concern and worry about the ill child. Well siblings also suggested that other siblings should be made aware of the fact that they will have to help the ill child more often. One sibling even went to the extent of saying that one may have to act as a "bodyguard" for the sick child. Examples of other responses to this question appear in Table 32. The most dramatic reply came from a 14 year old girl whose brother has Diabetes:

> If you want attention quick for a little while, you do something rotten so they've got to notice. Break something or don't tell where you're going or change personality type of thing. I spent a year being mad at everybody but it didn't do me any good at all. I was mad at everybody, especially my mother, but nobody really noticed. That's why I said to get attention do something really rotten.

Table 32

Examples of Advice Offered by the Index Group to the Well Siblings of Other Children with Chronic Illness

"You have to work harder for your brother or sister because they're going through a lot."

"Take good care of him--sometimes it's hard."

"Expect to be left out of the picture for the next six months. You won't get any attention. It'll be the main thing in your parents' mind."

"If mom's upset, realize what she's going through."

"Try not to treat him any different but still understand his situation. Feel for him. He may have more sensitive feelings at times."

"Don't be scared of your sister."

"Remind him to take his tests regularly. Watch what he eats."

"At first it's hectic. . . the whole household has to be readjusted."

"I sometimes think I'm going to get Diabetes. It's sort of bad because I get scared and think she's going to prick her finger and get blood and I hate to see blood."

"Look out for your sister because it's hard being sick. Don't worry; she won't die because they have medicine to ease it."

"You'll be helping your mom and doing lots of things for her."

"Try not to upset her because she'll make you feel guilty. Don't let her take advantage of her illness."

"It's normal, like having a normal brother."

"You get used to it after a while."

"Just stick it out and see how things go."

"You have to adjust yourself. You have to grow up a bit."

"Find out as much as you can about the disease. Take one day at a time."

CHAPTER 4 - DISCUSSION

The many findings on the adaptation of the siblings of chronically ill children in both the emotional and behavioral spheres and how they and their families compare with the matched control group will be discussed below. This will be followed by a more general evaluation and interpretation of siblings' responses to the semi-structured interview.

Between Group Differences - The Siblings

Partial support for the hypothesis that siblings of children with chronic illnesses would have significantly more emotional and behavioral adjustment problems at both points in time than siblings of children not afflicted with chronic illnesses was found. With respect to emotional adjustment, siblings of chronically ill children did not report lower levels of self-esteem (SAI) when compared to the siblings of healthy children at either data collection point. In contrast, however, the anxiety scores (WITF) of male and female siblings in the two groups differed from each other at each point in time. Furthermore, in terms of behavioral adjustment (BPC), siblings of children with chronic illnesses had significantly more behavioral problems as rated by their parents than siblings from families where there were no chronically ill children. The significantly higher incidence of shy-anxious behaviors on the part of the siblings of ill children and the stability of this finding over time were most remarkable.

The inclusion of a temporal dimension in this study differentiated the current investigation from previous studies and provided a more reliable and in-depth perspective of the personality functioning of siblings

of chronically ill children. For practical reasons the three month interval between data points was used. It should be noted, however, that in order to acquire an appreciation of the developmental process of adaptation, future studies examining a longer span of time between interventions are required. This study also differed from earlier research conducted on this population in its more rigorous design and utilization of objective, standardized measures of adjustment. Due to the more stringent methodological procedures adopted and the repeated measures analysis undertaken, the findings emanating from this project lend some clarification to the existing literature regarding the emotional and behavioral status of siblings of chronically ill children. This issue will be addressed further in the discussion that follows.

SAI

The absence of negative effects on the self-concept of siblings in this research is consistent with the work of Gayton et al. (1977) who studied siblings of children with cystic fibrosis. Nevertheless, this finding is inconsistent with other studies which have addressed themselves to the self-concept of siblings of children with chronic disorders. Cairns and colleagues (1979) and Klein (1975) both comment on the presence of a relationship between self-esteem of siblings and the existence of a chronically ill child in the family. On the basis of their study of the brothers and sisters of children with cancer, Cairns et al. (1979) declare that siblings' self-concept in the family situation is lowered. They contend that siblings frequently have a fear of confronting family members with negative feelings and have perceptions of their parents as overprotective and indulgent of the sick child. They also state that they found that the siblings of ill children in their study were more

generally concerned with failure. Klein (1975), upon investigating the impact of chronic kidney disease on family members, found a significant correlation between self-esteem and siblings' perceptions of their involvement with the child's disease. The greater the involvement, the lower the self-esteem of siblings in her study.

There are a few possible reasons for the discrepancy between the studies referred to above, all of which relate to methodological and/or theoretical issues. First of all, the comparability of the samples of subjects in the four studies is unknown. Secondly, there is variation in the instrumentation and use of control groups in the studies described. Cairns et al.(1979) did not include a non-clinical control group in their study. They just compared the siblings of children with cancer to the children themselves. Moreover, they based some of their results on responses to projective tests which are known to be of suspect validity and reliability . The results of Klein (1975) seem to be founded entirely on an interview procedure that she devised. Psychological assessment of the self-concept of siblings with well-known standardized measuring instruments did not occur. In contrast to these investigations, the findings of this study and of Gayton et al. (1977) did not rely on the researchers' subjective interpretation to any degree. Measures of self-concept which require self-report and have standardized instructions and objective scoring criteria were administered, thus reducing bias in the results. Finally, the current investigation involved a longitudinal perspective while the others did not. In light of the latter, the results of this study can be argued to be more reliable than the results of the studies which did not include a temporal dimension.

Although the use of a standardized, objective measurement device

is a more systematic experimental technique and one which permits greater credence and generalizability of results, it is also possible that the SAI and self-concept measures which were used by this researcher and Gayton et al. (1977) were not sensitive enough to pick up on the effects of the chronic illness experience on siblings' feelings about themselves. Furthermore, the SAI may not be sensitive to changes over time. Clearly, the measures have limitations because their items are not disguised and the possibility of socially desirable responding on the part of the siblings of ill children which made them appear similar to control siblings must be considered. However, as will be discussed shortly, the measure of anxiety employed for the purposes of this study contained a Lie-Defense scale and siblings of chronically ill children were not found to differ significantly from siblings of non-ill children on this scale. The latter argument, therefore, loses some of its meaningfulness.

A third plausible explanation for the discrepancy in the findings of investigators who have examined the self-soncept of siblings of ill children relates to the different medical illnesses under scrutiny in each study. Though this research assumed a homogeneous conceptualization of chronic illness (i.e., certain classifications of chronic illness (e.g., medical, cosmetic) can be viewed as similar) and the illnesses in all four studies were "medical", it may be that the specificity conceptualization of chronic illness does merit consideration. Though there are several commonalities amongst the chronic diseases considered in these studies, there are also differences. It may be that specific characteristics alone or in combination produce differential effects on siblings' adjustment. Specific characteristics of cancer and kidney disease, therefore, may have different effects on siblings' self-concept than JRA, Diabetes, Gastrointestinal disorders, and Cystic Fibrosis.

It might also be that a moderator variable(s) accounts for the relationship between level of self-esteem and having a sister/brother with a long term medical condition. As Kelin (1975) found, the sibling's perception of the size of his/her burden of care for the sick child was correlated with self-esteem. In both the present study and that by Gayton et al. (1977), aside from age and/or sex, the intervening role of specific characteristics of siblings was not examined.

It is interesting to note that the results of the current study are consistent with the more recent research with regard to self-esteem of chronically ill children. More explicitly, the findings that are now emerging on the self-concept of children who have long term illnesses suggest no significant differences between ill and healthy children (e.g., Kellerman et al., 1980).

WITF

The findings of a significant drop in reported anxiety scores at the second point in time the WITF was administered and of differences in the anxiety levels and the way that male and female siblings in the index group expressed their anxiety at both points in time when compared to male and female siblings in the control group were most interesting.

In view of the fact that the anxiety scores of siblings in both groups decreased at the time of the second interview, especially their Worry-Oversensitivity (WO) score, it seems likely that increased familiarity with the interviewer, the interview procedure, and the WITF itself account for this result. What was particularly interesting and unexpected with regards to the WO subscale was that, at the time of the first interview, the mean scores of both male and female siblings in the control

group exceeded those of male and female siblings (though not statistically significant) in the index group. That is, to the researcher's surprise, the siblings from families where there were no ill members reported more anxiety in the form of worry and oversensitivity than the siblings from families where there was a child with a chronic medical condition. This finding was very exciting because it is consistent with the position of crisis theorists (e.g., Caplan, 1974; Golan, 1978) who purport that major life crises can have a growth producing effect. In the context of this study, it is possible that siblings of chronically ill children develop heightened stress tolerance as a result of their illness experience and cope better with novel and therefore stressful situations than siblings from families in which all members are healthy.

Sex differences in anxiety were predictable on the basis of empirical studies pertinent to the statistical properties of the WITF which found that females scored significantly higher than males (Reynolds & Richmond, 1978). Nevertheless, the existence of group differences which interacted with sex differences and time differences on this anxiety measure imply that the experience of having a chronically ill sister/brother does have a measureable and particular effect on the level and form of anxiety expressed by siblings of such children. The data was complex though and there did not seem to be a specific theoretical explanation for this three-way interaction. What was clear, however, was that there were differences between male and female siblings of children with chronic illnesses and those without chronic illnesses in terms of anxiety levels and how anxiety was expressed. The utility of conceptualizing and measuring anxiety as a multidimensional construct was also suggested.

These findings add support and clarification to Farber (1959, 1960), Binger (1973), and Binger et al. (1969). In each one of these reports, increased anxiety in the siblings of children who were mentally retarded or diagnosed as having cancer was commented upon but again, the necessary experimental rigor to uphold this observation was lacking. The use of adequate sample sizes, control groups, valid and reliable assessment tools and a prospective analysis with a repeated measures component were conspicuously absent from these reports. Furthermore, in these studies, anxiety was viewed as a unidimensional construct.

BPC

The finding that siblings of chronically ill children were more maladjusted in their overall behavioral functioning than the siblings of children who were not sick was expected on the basis of the available research to date. In accordance with the latter, it was not surprising to observe that the mean of each subscale of the BPC was higher for the siblings of chronically ill children at both interviews suggesting that they engaged in an increased incidence of immature, anti-social, and shy-anxious behaviors when compared to their matched controls. Findings such as those of Tew and Laurence (1973) who documented a four fold increase in social adjustment problems (type unspecified) for siblings of children with spina bifida when compared to a control group were preparatory in this regard. What was unanticipated was the finding that the largest difference between siblings in the two groups was in the incidence of shy-anxious behavior. Both times parents were asked to rate the behavior of the child in their family who was participating in this study, siblings of sick children were described as engaging in almost

twice as many behaviors of a shy-anxious nature than siblings from families without an ill child.

While it is possible that the obtained results can be accounted for by the particular clinical sample employed in this study (i.e., sampling error), one must also consider that this was a "volunteer" sample. As pointed out by Rosenthal and Rosnow (1969), volunteers are better educated, less authoritarian, more sociable, higher in self-disclosure, and better adjusted on the whole than non-volunteers. The results attained in this investigation suggesting behavioral pathology may therefore be an underestimate of the true degree of social adjustment problems in the population of siblings of chronically ill children. They also likely reflect actual differences between siblings from the two types of families represented in the study.

As already indicated, this was not the first study to systematically examine the behavioral adapatation of siblings in families with a chronically ill child member and find evidence of behavioral pathology. However, it was original in its use of more than one data point and in its inclusion of fathers as well as mothers in the ratings of siblings' behavior. Both of these factors strengthened the reliability of the findings that emerged and helped elucidate the existent research.

Interestingly, a comparison of the present study's findings with those of other available reports on the behavioral adjustment of siblings of children with long term illnesses suggests that medical or physical disorders may have a different impact on social functioning than disorders which have a mental component. Lavigne and Ryan (1979), in one of the few rigorous studies of siblings of chronically medically ill children,

obtained results consistent with those of this investigator. Increased rates of social withdrawal and irritability when compared to a non-clinical control group were found. Similarly, uncontrolled observational and interview studies support the notion that siblings of children with chronic medical illnesses respond to this experience with more behaviors of a neurotic withdrawn and shy style (Binger, 1973; Binger et al., 1969; Cairns et al., 1979; Peck, 1979; Taylor, 1980). Directly opposed to these findings are those of Gath (1973) and Tritt (Note 4) both of whom systematically and objectively assessed the behavioral adjustment of the siblings of mentally retarded children and report an increased incidence of anti-social behaviors and not of shy-anxious behaviors.

This is not to say that no evidence of anti-social behavior was found for siblings of chronically medically ill children, or conversely, that no evidence of shy-anxious behavior was found in the group of siblings of retarded children. It seems quite apparent that there is an increased incidence of overall psychopathology in siblings of children with chronic disorders generally, and that both problems of conduct and personality do occur regardless of the type of chronic illness. However, it also seems that the type of illness (physical-medical vs mental) may provide some differential prediction of the form of social maladjustment most likely to be manifest. Further research will be necessary to address this hypothesis.

Summary and Conclusions

It is of importance to note that chronic illness in a sister/brother

may affect siblings' anxiety level and result in increased displays of shy-anxious behavior. Nevertheless, adverse consequences do not necessarily occur in relation to the experience of having a chronically ill brother/sister. Some evidence that can be interpreted in support of the postulation of the growth producing effects of crisis and stress was found. In addition, no evidence of a reduction in self-esteem was documented. The picture, therefore, may not be as bleak as the literature to date would have one think and indicates the need to adopt a less pathology oriented view of the effects of the chronic illness experience on siblings' adjustment. It also seems imperative to commence study of the possible positive effects of this experience and for future research to continue to examine sibling adjustment from a longitudinal perspective with sophisticated methodological techniques.

Between Group Differences - The Families

The hypothesis that families in which there was a chronically ill child would report lower levels of functioning at both interviews than families in which there were no chronically ill children was not statistically supported. Families of sick children had lower mean scores on the FFI at both time frames than families where all members were healthy but the differences between the groups were not statistically significant. A significant decrease in FFI scores at the time of the second interview was found, however. This was true for both groups and probably reflects the increased honesty of families at the second interview.

There are a few plausible explanations of why the hypothesis of group differences in family functioning was not validated. One explanation

pertains to the measuring instrument utilized to assess family functioning. Since this was only the second known study to attempt to systematically examine family functioning in relation to childhood chronic illness, it was decided to employ the same measure as was used in the initial study (Pless et al., 1972). As described earlier, this instrument had adequate validity and reliability data, was quickly administered and scored, and had provided a discriminating dimension in the Rochester Child Health Survey. Unfortunately however, subsequent to the completion of data collection for the present study, Pless (Note 3) cautioned against the use of this measuring device except "within very broad limits." The sensitivity of the FFI must therefore be questioned as must the appropriateness of its use in this investigation. Although composed of more than one dimension of family functioning, the FFI has very few items and its adequacy as a multidimensional measure is suspect. Furthermore, the FFI can also be criticized for the transparency of its questions which allows subjects to respond in a socially desirable manner. It is thus possible that the parents of chronically ill children disguised negative aspects of their family life in order to portray their family in a more positive and better adjusted light.

The second explanation for the lack of statistical support for this hypothesis has to do with the volunteerism issue. As discussed above, Rosenthal and Rosnow (1969) present evidence which indicates that volunteer subjects are better adjusted socially and emotionally than non-volunteers. Thus, it is possible that the families of chronically ill children who volunteered to participate in this study may have been better adjusted psychosocially than those who did not volunteer or the general population of families with a chronically ill child member.

Another viable explanation for the failure to support this hypothesis is that the turmoil associated with adjusting to a child's chronic illness may substantially subside with the passage of time. Though this researcher's original intention was to examine families who were between three and twelve months post diagnosis of the chronic illness, this was not possible. Only five families who were within this range were identified and volunteered to participate. The average amount of time that had elapsed since diagnosis was three years, seven months. Consequently, time may have allowed resumption of normal levels of family functioning. This interpretation is supported by the work of Kellerman et al. (1980) who found that length of time since diagnosis is an important variable when assessing the psychosocial adaptation of chronically ill adolescents.

Due to the weaknesses of the FFI as a measure of family functioning as well as the other explanations provided above for the lack of support found for this hypothesis, a definitive statement about how the index group compared with the control group is not possible. Thus, examination of the level of functioning of families with a chronically ill child should be undertaken in future investigations. Better measures of this construct are necessary before continued study occurs, however. The use of observational/interactional methods of analysis as opposed to self report measures should be considered. In addition, because of the fact that FFI scores did change significantly over time, albeit for both groups of subjects, it seems important to persist in studying family functioning on a more longitudinal basis than in this study, perhaps starting at the time of diagnosis. Furthermore, inspection of the range of scores on the FFI revealed wide fluctuations, suggesting that it may be of benefit to look at each family individually rather than as part of

a group.

The findings regarding differences between the index and control groups in the amount of leisure time parents reported spending in recreational activities with their well children and the amount of change experienced between the two interviews provides added impetus for sustaining a research focus on family functioning.

Recreational Activities. Both parents from families where there were no sick children independently reported spending greater amounts of time engaging in leisure activities with their well children than mothers and fathers from families where there was a chronically ill child. The largest difference occurred for fathers in the two groups.

Due to the fact that the index and control groups were very well matched, it seems reasonable to attribute the differential estimates to the one distinguishing factor between them, i.e., the presence or absence of a child in the family with a long term medical disorder. It would appear then, that when there is a sick child in the family, especially one whose condition demands daily treatment/management on the part of parents, the extra time required of parents is taken from that normally spent in leisure with the other child(ren) in the family. This argument gains support from the data indicating the actual amount of time parents (particularly mothers) spent in treatment/management tasks dictated by the chronic disease. Averaging across all parents, it was found that mothers of ill children spent 3/4 of an hour daily and that fathers spent approximately 1/4 of an hour daily with the sick child.

Actual documentation of decreased leisure time with the well children

in families with a chronically ill child has not been reported prior to this study but, there are numerous anecdotal comments, clinical impressions, and observations in the literature which add further sustenance to this finding. Oakley and Patterson (1966), Meyerowitz and Kaplan (1967) and Zeidel (1973) are among those who have commented on the reduction and even curtailment of recreational activities in families with a child who has Leukemia, Cystic Fibrosis, and Diabetes, respectively. Since the index families who took part in this study were volunteers and, as already delineated, volunteer samples are often more social and better adjusted than the population they represent, it may be that the average amount of time this group of index parents calculated for leisure was an overestimate of the amount of time spent by index parents in general. That is, the difference between mothers and fathers in the two groups in reports of leisure time spent with their well children may actually be greater than found in the present study.

Do the healthy children in these families realize they are not privileged to as much leisure time with each of their parents as their counterparts from families with no sick members? How do they feel about this inegality if they are aware? Are parents aware that the time they devote to treatment/management dictated tasks may be borrowed from and at the expense of their healthy children? How can we help the parents and siblings of chronically ill children deal with this situation? These issues deserve attention from both a clinical and research position.

Change Experienced Between Interviews. Sixty-five percent of the parents in the index group said that significant changes had occurred for their family between the two scheduled appointments, whereas only

26% of control group parents acknowledged this. Furthermore, 59% of those in the index group who claimed there were changes identified changes that were related to the ill child's medical status. Parents referred to a worsening of the sick child's condition, increments in dosages of medication for the child with the illness, increased irritability on the part of the sick child, greater parental involvement in a support group, the achievement of remission for a child, trying out a new diet and mode of treatment for the sick child, and the assumption of more responsibility for treatment/management by the chronically ill child. Thus, changes which can be seen as having both positive and negative consequences for family members were indicated.

Holmes and Rahe (1967) and Coddington (1972a) contend that events that require a readjustment on the part of an individual, a change in his/her life, constitute a stress or psychological trauma. They point out that this definition is very broad and includes events with a positive as well as a negative connotation. On the basis of their research on the significance of life events for adults (Holmes and Rahe, 1967) and children (Coddington, 1972a), they also state that a number of rather insignificant events occurring during a given period may add up to a greater stress than a single, obviously traumatic event and that stress and psychological trauma are a cause of psychopathology.

The question of how much psychological readjustment the average child can be expected to undergo in the course of a year was addressed by Coddington (1972a, b). He quantified readjustment in terms of Life Change Units (LCU) and then constructed a normal growth curve on which an individual child's experience can be plotted and compared. Although the curve was not formally used in this study, it does appear that siblings

in the index group were required to make more readjustments in the course of the time of this study than siblings in the control group. On this basis, they may be more at risk for psychopathology. Direct study of this factor with a more longitudinal research design, i.e. one that more closely scrutinizes and compares the accumulation of stressors over time for siblings of chronically ill children and a control group seems relevant.

It is quite possible that the greater number of changes reported in the lives of index group families was connected to the larger decrease in FFI scores of these families, as described earlier, when compared to control group families at the time of the second interview. Furthermore, preliminary evidence to suggest that family functioning plays a role in terms of the behavioral adjustment and honesty-defensiveness of siblings of chronically ill children was found. Most importantly, there was a suggestion that behavioral difficulties, especially those of an anti-social nature, were more often reported in conjunction with lower FFI scores. This will be elaborated on in a later section of this paper.

In summary, the findings and research reviewed regarding change, time spent in recreational activities, and the relationship of family functioning to the adjustment of siblings lends support to the previously stated recommendation that continued investigation of this variable is merited.

Impact of Moderator Variables on the Adjustment of Siblings of Chronically Ill Children

Of the five variables examined as potential moderators of the psycho-social adjustment of the siblings of chronically ill children only two,

i.e., the amount of time spent by mothers daily in management/treatment activities with the sick child and level of family functioning, received statistical endorsement. Interestingly, both of these variables pertained to characteristics of the siblings' family. Neither of the characteristics of the siblings (age, sex) nor the differentiating feature of the illnesses (stability of prognosis of the ill child's disease) studied were empirically validated as predictors of good or poor adjustment on the part of siblings. Each moderator variable will be discussed separately below.

Time Spent Daily by Parents in Management/Treatment of Ill Child

The finding of a significant relationship between mothers' daily involvement with the ill child and the emotional adjustment of the well siblings in this study extends the work of Taylor (1980). She questioned 25 siblings of children with chronic medical illnesses directly about the impact of this experience and reported that two of the aspects of the illness experience that had the greatest impact on siblings were the parent-ill child relationship and the medical care and treatment of the ill child. Many siblings described feelings of being alone and saw the parents and ill child as dyads that excluded them.

No evidence of an association between this variable and behavioral adjustment is reported in the literature. Nor was data in support of such a relationship found in the analysis of time spent daily by mothers with the ill child and social functioning of siblings. Furthermore, the amount of time spent by fathers daily in treatment/management activities did not seem connected to the adjustment of the well children in families with a chronically ill child.

The finding of differences between mothers and fathers in these families does not seem surprising when one examines the average estimates reported by parents of time spent daily in these activities. As alluded to previously, fathers typically spent 14 minutes a day in treatment/management activities, whereas mothers spent approximately 44 minutes a day. It therefore, appears that mothers generally carried the bulk of the load in terms of care for the ill child and that fathers were relatively uninvolved in the caretaking activities related to the ill child's medical status. Also worthy of note is the fact that the majority of mothers (60%) were employed outside the home. Thus, mothers of sick children not only had the regular dual responsibilities to their careers and their family, but also assumed the job of carrying out treatment/management activities necessitated by the ill child's condition.

In light of the triple role carried by mothers of ill children, a relationship between time spent in treatment and the anxiety levels of the well children in the family was not unexpected. Nor was it particularly surprising to find that, of all the clinical subscales of the WITF, the WO subscale had the strongest relationship to time spent by mothers with the ill child. The more time spent by mothers in treatment/management tasks, the greater the anxiety levels, especially worry and oversensitivity, of the well children in the family. This was observed at both interviews, i.e., there was no indication that anxiety levels subsided with the passage of time.

One plausible explanation for this finding may be that a modelling effect occurs whereby the well children in these families emulate the reactions of their mothers to the illness experience. Klein (1975) found that mothers of children with chronic renal disease were more anxious and

less happy in comparison to other populations and, their adjustment was correlated with the size of the burden of the child's care they assumed. In the current study, most mothers played three concurrent roles (employee, parent, caretaker of ill child) and, as revealed above, carried most of the burden of treatment/management of the ill child alone. Therefore, they very likely experienced anxiety, frustration, resentment, and a host of other feelings directly related to this state of affairs.

Another feasible reason for the association between siblings' anxiety and time spent daily by mothers with the sick child may rest with the messages and/or interpretations involvement, especially in large doses, had for siblings. Maybe they equated more intensive involvement with either a more serious condition and poorer prognosis and were scared by this, or perhaps they felt less loved and favoured by their mothers and were threatened with feelings of insecurity in this regard.

In contrast to the stable impact of time spent daily by mothers on the anxiety level of siblings, their self-esteem did seem to vary over the two interviews when examined in conjunction with the variable of mothers' involvement with the ill child. Although at the time of the first interview siblings' self-concept on the General, Family, and Peer subscales of the SAI decreased as mothers devoted more time caring for the ill child, this was not the case at the time of the second interview. This finding is interesting for two reasons. First of all, it suggests that though siblings' self-regard was initially vulnerable and affected adversely by increasingly large amounts of time their mothers spend with their ill sister/brother, they were able to recoup their self-esteem over time. Perhaps they got used to their mothers' involvement with the ill child or maybe they were able to rationalize it. It may also have been

that at the time of the first interview, other events occurred which contributed to decreased self-concept in these areas. Whatever the explanation, persistent effects on their self-concept were not observed. Secondly, even though at the first interview most dimensions of self-concept were affected negatively by mothers' involvement with the ill child, siblings' self-esteem with respect to school achievement was not affected. It may be that the effects on self-concept are not all encompassing, but rather, have more to do with interpersonal relationships. Perhaps, when the illness experience is a relatively new one and/or other stressful events are occurring simultaneously, siblings begin to doubt their personal worth in the context of family and peer relationships when their mothers devote extra attention to their ill brother/sister. This does not generalize to the school setting, however. With the passage of time these self-doubts may subside.

What was somewhat unexpected was the finding that behavioral adjustment of well siblings bore no relationship to the amount of time spent by mothers in treatment/management tasks. One might anticipate that siblings would react overtly by either manifesting anti-social, withdrawn, or immature behaviors to the increased attention provided by mothers to their sister/brother. Instead, in this study evidence of more covert and internalized reactions, i.e., anxiety, was found. Though speculative, it could be that siblings of sick children made a conscious effort not to express their feelings overtly. In the semi-structured interview several siblings made mention of the fact that they attempted to take their parents' feelings into consideration and not create extra stress for them. They saw a need to cooperate and comply more with their parents. Extrapolating from this, one would then expect to observe fewer behavioral problems

and more emotional problems in relationship to the time in treatment variable.

These findings and explanations are tentative. No other studies have assessed this variable systematically. However, in view of the present investigation's findings, it does seem important to continue examining the moderating role of time devoted to treatment by parents and, concomitantly, to educate the parents of chronically ill children of what the potential effects of their involvement with the ill child may be on their other children. Information about the significance of discussing issues related to the care of the ill child with siblings and providing them with explanations of the need for such daily involvement might also be given to the parents in such families. Support and assistance in carrying out these educational objectives will likely be necessary and should be given as well. Repetition of this information and follow-up via monitoring of families on a regular basis may also prove beneficial, in light of the suggestion that adjustment may vary over time. These services need not be provided strictly by medical personnel. There appears to be a role here for social workers and psychologists. Given the psychosocial implications of the chronic illness experience, the medical model adhered to presently seems in need of replacement by a more social-ecological model. Finally, the fact that mothers spend much more time on the average than fathers in the care of a chronically ill child member needs to be addressed. Despite this study's finding of a positive correlation between the amount of time spent in management/treatment activities by mothers and fathers within each family, fathers in all families with an ill child should be encouraged and helped to assume a more regular and active role in the care of this child. Perhaps if the

responsibilities are split more evenly between mothers and fathers, more time will be available for mothers to spend with their other children and the likelihood of adverse effects on their emotional adjustment will be diminished.

Level of Family Functioning

This was the first empirical study to test the hypothesis that siblings of chronically ill children from low functioning families would have significantly more emotional and behavioral adjustment problems than siblings from high functioning families. In this context the results that emerged are promising, but equivocal. Although FFI scores did not discriminate between siblings from high and low functioning families in the emotional sphere of functioning, some support for the importance of assessing family functioning as a means of predicting the behavioral adjustment of siblings was found. However, this effect was not stable over time. The level of family functioning at the time of the first interview only was associated with the behavioral functioning of the siblings of chronically ill children.

Examination of the pattern of BPC scores within the high and low functioning groups was also revealing. It showed that while the highest subscale score for siblings in the low functioning group was clearly on the CP dimension at both interviews, the PP dimension of siblings in the high functioning group was most elevated or very similar to the CP dimension at the two interviews. This finding adds further validation to the stated hypothesis. It suggests that siblings from families with

these two different levels of functioning may manifest different behavior problems in response to living with a chronically ill sister/brother. This finding may have important interventive and preventitive implications and should be further examined in future investigations.

Two questions arise from the findings. First of all, why did family functioning have an impact on behavioral adjustment and not on emotional adjustment? With respect to this question, the issue of who rated siblings on the measures of emotional and behavioral adjustment is relevant. In the present study, siblings rated their own levels of anxiety and self-esteem whereas parents rated their behavioral adjustment. It is therefore possible that differences in the two spheres of functioning were the result of this factor. Perhaps, had parents rated their children on all measures, or vice versa, had the children rated themselves on all measures, more consistent findings would have emerged. It is also plausible that the time elapsed since diagnosis accounts for this finding. As pointed out earlier, an average of 3 years, 7 months had passed since the diagnosis of the illness in this sample of families. It may be that initially there were also differences in the emotional adjustment of siblings from high and low functioning families but that over the course of time they resolved and only behavioral differences persisted.

The second question stemming from these findings is why did FFI scores at the first interview significantly discriminate between the behavioral adjustment of the two groups but not at the time of the second interview? Is this a spurious finding? Which data point is correct? It seems possible that both these findings are accurate. The largest difference between the groups at Time 1 was on the CP subscale of the BPC, with

siblings in the low functioning group rated as having a two fold increase in the incidence of anti-social behaviors when compared to siblings in the high functioning group. At the time of the second interview though, there was a significant decrease in the reported rate of anti-social behaviors for all siblings in the index group, but most noticeably for siblings from families with low levels of functioning. Their scores on the CP subscale dropped twice as much as those of siblings in the high functioning group. Due to this large decrease for siblings in the lower functioning families, the two groups were more similar to each other in terms of incidence of anti-social behaviors at the time of the second interview. If the scores at Time 2 represent the beginning of a plateau, it may be that siblings from low functioning families needed the extra time in between interviews to deal with their brother's/sister's illness and to calm down behaviorally and reach more or less "normal" levels, whereas those in the high functioning group did not. It is also possible that the first interview conducted for the purposes of this study had a therapeutic effect on the families who participated, especially those with low levels of functioning. That is, it may have sensitized both siblings and parents to family issues. Certainly these explanations must be viewed as tentative, particularly the former because of the amount of time that had elapsed since diagnosis and because behavioral adjustment was only measured on two occasions. In addition, the size of the current sample was fairly small and, as discussed above, the FFI no longer seems the measuring instrument of choice.

Further research using longitudinal designs with several data collection points, a larger sample size, and a better measure of family

functioning is definitely called for. Pless (Note 3) and Binger (1973) reinforce this recommendation by their respective statements that, family functioning is a potentially powerful predictor of those at high risk and, the reactions of siblings are determined by the extent to which the illness becomes intertwined with family dynamics.

The implications of family functioning for intervention and prevention are far reaching. Routine assessment of this likely moderator variable around the time of diagnosis and periodically thereafter, may prove useful, as discussed earlier. Parents could then be given information about what type of "typical" reactions and/or problems to expect from their healthy children, how long they will last, and how they might prevent and/or handle any difficulties that arise.

Stability of Prognosis

Despite the absence of statistical support for the hypothesis that siblings of children with chronic illnesses marked by instability of prognosis, i.e., periods of remission and exacerbation, would have significantly more emotional and behavioral adjustment problems than siblings of children with chronic illnesses not characterized by instability of prognosis, the semi-structured interview permitted some scrutiny of this variable and indicated its pertinence. However, support for the importance of this feature of an illness was in the reverse direction than predicted. That is, it seemed that the siblings of children with Diabetes, which tends to be more stable than the other diseases included in this study, were more stressed and less content with their

family situation than siblings of children with JRA and Gastrointestinal disorders.

The siblings of children with Diabetes were much more likely to complain about having extra chores and responsibilities at home because of having a sick sister/brother than were their counterparts from the other two illness subgroups. They also seemed to be more resentful of this state of affairs and many siblings made it quite clear that they believed that their brother/sister was treated more leniently than they were. Related to this finding, the majority of siblings of children with Diabetes perceived the sick child in the family as being the recipient of "special treatment" and they did not change their mind about this over the course of the two interviews. Material as well as emotional benefits to the sick child were pointed out. Many siblings in the other two illness subgroups offered contradictory responses about the special treatment question at the first and second appointments. It seems likely that their change of mind may have been related to a remission or an exacerbation in the condition of the ill child in the family, since the three illness subgroups were quite well matched with one another except on this characteristic of the illness.

This is the first study on the psychosocial adjustment of siblings of chronically ill children to entertain and examine the role of the stability of prognosis. The literature that is currently available with respect to this moderating variable refers only to its impact on children afflicted with a chronic illness. The most systematic study in this regard (Kellerman et al., 1980) found that adolescents whose physicians rated their prognosis as "stable" (e.g., Diabetics) were significantly less trait-anxious than were those patients (e.g., JRA, Oncologic) with

prognosis ratings of "improvement", "deterioration", or "uncertainty". Prognosis did not relate in any significant way to self-esteem or locus of control.

That an unstable prognosis would be more stressful for an ill child and perhaps, his/her family than a stable one, seems intuitively logical. At the same time, it is not difficult to comprehend why the siblings of children with a more certain prognosis, i.e., Diabetes, are disturbed by the ongoing parental attention to the ill child, dietary modifications (often imposed on the entire family unit), and the extra chores and responsibilities they feel they are asked to assume. They are constantly being reminded of the ill child's condition and seem to repeatedly witness what they perceive as differential and unequal treatment between themselves and their sister/brother. Siblings of children with less stable prognoses, i.e., JRA and Gastrointestinal disorders, may not experience these events and feelings on a continual basis. The ill child may become the central focus of the family only at the time the disease is active. When the disease is in remission, they may be able to resume normal living patterns where they are privy to the central role in the family at times.

The findings of this investigation may be spurious, a result of the particular sample and illnesses studied. Nevertheless, they indicate the need to look at this moderator variable more seriously with a much larger sample and wider variety of illnesses. They also suggest the possibility that this feature of an illness may have dissimilar effects on sick children as opposed to their siblings. Finally, should stability of prognosis turn out to be a significant moderator of sibling adjustment, there may be a need to look at families of sick children less homogeneously

and on more of an individual basis. Tailoring of intervention/prevention to the specific characteristics of an illness may be appropriate.

Age of Sibling

Clear support for the hypothesis that older siblings of chronically ill children would be more maladjusted at both data points than younger siblings was not found in this study. The older group of siblings of chronically ill children did not differ significantly from the younger group in terms of behavioral adjustment, and though differences in emotional adjustments were evidenced, i.e., siblings in grades 7 to 12 were found to have lower self-concept scores than those in kindergarten to grade six, particularly in the context of the family as well as more generally, this age effect was found for siblings in both the index and the control groups. As such, one cannot attribute the lower scores of the siblings in higher grades to the presence of a chronically ill sister/brother in the family. Interestingly, the older group of siblings was found to be less defensive than younger siblings on the Defense-Lie subscale of the WITF, but again this was true for the entire sample and was not specific to those older siblings in the index group.

While these findings may be explained in a developmental framework, given the tendency of younger children to be less honest and more defensive, it seems plausible that younger siblings may have experienced the same effects on their self-concept as older siblings but denied their existence.

The results of the present study are consistent with those of Lavigne and Ryan (1979) who conducted a rigorous investigation of the

psychosocial adjustment of siblings of pediatric hematology, cardiology, and plastic surgery patients. They are also in line with the findings of Tritt (Note 4) and Dunlap and Hollinsworth (1977) who examined the adjustment of siblings of mentally retarded children.

Despite the lack of statistical support for age as a variable which moderated adjustment specifically in the index group, it seems premature to dismiss this variable entirely. An argument for age to be considered a pertinent moderating variable in families with a chronically ill child member can be made on the basis of this researcher's observations of age differences in siblings' responses to questions on the semi-structured interview that was administered. For example, it was found that older siblings provided more intellectualized and less egocentric answers to questions, whereas younger siblings were quite self-focused in their replies. The implications of this still need to be addressed and should not be overlooked. It must also be remembered that the index group was composed of volunteers and this factor may account for the present results.

Finally, it is possible that the relationship between age and adjustment may be more complex. It may interact with other variables including those which have already been discussed and gender of sibling. Examination of such interactions was not undertaken in this study because of the inadequate sample size for this purpose and the dangers of performing analyses and generalizing their results when samples are small. Prior to age being jettisoned as a moderator of sibling adjustment in families with a chronically ill child, however, study of its interaction with other variables should be conducted.

Gender of Sibling

Differences between female and male siblings of chronically ill children when compared to the control group were found on the anxiety measure at each data point, but the precise nature of these differences was unclear. Male and female siblings did not differ in their frequency or manifestation of behavioral problems or in their reported levels of self-concept. Consequently, substantiation of the hypothesis proposed regarding greater emotional and behavioral maladjustment in females is lacking.

The results regarding no sex differences in self-concept are consistent with Tritt (Note 4) who studied siblings of retarded children. Likewise, those with respect to anxiety level concur with Farber (1959, 1960) and Lavigne and Ryan (1979), both of whom found evidence of sex differences in anxiety though in opposite directions. In contrast, the results pertaining to behavioral adjustment are not in accordance with either those of Gath (1973) or Lavigne and Ryan (1979). Gath (1973) observed a greater incidence of anti-social behavior in female siblings of retarded children, while Lavigne and Ryan (1979) found evidence for greater displays of anti-social behaviors on the part of male siblings of sick children.

Both the consistencies and inconsistencies delineated may be accounted for by the measuring instruments employed in the various studies. Both studies that examined the self-concept of siblings utilized the same measure and emerged with similar results. In contrast, wherever discrepant findings were noted different measuring devices were utilized to assess the same construct. Until comparable, valid, and reliable

instruments are used across studies, it will be difficult to sort out the confusion in the literature and make definitive statements about whether and how gender affects adjustment. The accuracy and importance of the present study's findings awaits the results of future investigations.

As with the age variable, another reason for the existent confusion about the role of gender may be that its relationship to psychosocial adjustment is complex and can only be determined in conjunction with the examination of other variables. The work of Lavigne and Ryan (1979) supports this notion. They found that the relationship between age of the well sibling and adjustment in their study could not be comprehended without inspection of sex of siblings. Inclusion of this variable in their analyses revealed that sex and age were both relevant variables, and when examined together provided the greatest contribution. Again, due to the sample size, this was not possible in the present study, but should be considered in future studies.

Summary and Conclusions

The examination of variables that may play a role in either allaying or aggravating the effects of living with a chronically ill child on siblings was enlightening. Most significantly, it provided support for the frequent allegations in the literature regarding the important role played by family variables in influencing adaptation. Validation of two such family factors, i.e. amount of time devoted daily by mother to treatment/management of the ill child and level of family functioning,

allowed speculation regarding implications for prevention and intervention with families of chronically ill children. The need to assess family functioning on a regular basis and to routinely give parents information about the effects of having an ill child in the family was stressed. More active involvement of fathers in the care of the ill child was also recommended. Moreover, the need to move from a purely medical model to a more holistic-ecological framework of childhood chronic illness was advocated.

Although empirical confirmation for the role of gender and age of sibling as well as the stability of the prognosis of an illness was not found, it would seem premature to dismiss these variables as moderators of adjustment and discontinue study of them. Larger sample sizes which permit scrutiny of the interaction of these variables may add clarification to their role. Furthermore, inclusion and analysis of open-ended responses of siblings in addition to their forced-choice responses should be considered in evaluating these potential moderator variables.

Additional Findings Pertaining to the Index Group: Perceptions of Support

The data collected pertaining to affiliation with support groups and adequacy of current levels of support indicated that more attention to resources for families of chronically ill children and their use is required. Only seven of the families who participated in this study were affiliated with a support group. Most of these families (5 or 71%) had a child member with Diabetes, while the remainder had a child with a Gastrointestinal disorder (2 or 29%). None of the families with a

child who had JRA belonged to a support group. This was very surprising until this researcher was informed that services for families of pediatric patients were not offered at the local arthritis association.

Despite the fact that support services were available to the parents of children in the other illness groups, 60% of those with a Diabetic child stated that they needed and wanted more support. Three of these families were receiving the services of the Canadian Diabetes Association, while three who declared they needed more support were not members of this association. Likewise, two of the families who had a child with a Gastrointestinal disorder expressed the desire for increased levels of support even though they were members of the Canadian Foundation of Ileitis and Colitis and Associated Diseases, while three families did not belong to this group. Half of the families of children with JRA stated that they felt the need for greater support services.

What kind of support services were requested by parents? In all three illness groups, more support from the hospital clinic where their child was being treated was identified as necessary. Though most parents generally seemed to view the clinic in a favorable way, some said that they would like the hospital staff to answer more of their questions about daily living; a few commented that more time with the doctor would be helpful because they often felt rushed by him/her and left appointments "frustrated"; and one set of parents commented on the medical terminology used by doctors and nurses which they found very hard to follow and comprehend. Parents also revealed that they were dissatisfied with the type and amount of support they received from friends and relatives. Many complained that there was a lack of empathy and

understanding on the part of others. A few parents in all three illness groups claimed that their friends and relatives "were not there when we needed them" and that "they think they have all the answers". Parents in a couple of families stated that they would like more "physical support." They pointed out that since their child had been diagnosed, they had never been away on their own because they did not know with whom to leave the ill child. They expressed the wish to be part of an exchange holiday program with other families where there was a child with the same illness. At least one family from each illness group also mentioned that they would like the opportunity to meet with other parents of children with chronic illnesses and discuss their similar experiences, ways of coping, and strategies for handling situations that arose regularly. One parent even said,that because she would have like to meet with parents who were going through the same thing she was, she planned on starting a program where home visits would be made to families with a newly diagnosed child and periodically thereafter to provide support and to "let them know how to handle things."

Lack of support from the medical community as well as relatives and friends in relation to chronic medical illness in a child member of the family has been documented by others (Kelly, 1979; Meyerowitz & Kaplan, 1967). Linder (1970) and Heffron Bommelaere and Masters (1973) respectively describe short-term group therapy experiences designed to provide support for mothers of handicapped children and children with cancer. The chance for ventilation of frustrations, fears, and other feelings stemming from the experience of living with a chronically sick youngster coupled with support from others who were undergoing the same stresses was a major aspect of these groups and was perceived by all

involved as being very beneficial.

Extension of this type of group to mothers and fathers of children with other chronic medical illnesses seems appropriate, given the comments made by both parents in this study. Aside from sharing feelings and issues related to the ill child, parents may also be able to gain support and strategies of how to deal with the other children in the family and their feelings of spending insufficient time with their healthy children. This service could be provided by local support associations or by the hospital the child attends for treatment. It could be leaderless, i.e., of a self-help nature where no mental health professionals participate, or alternately, it could be lead by a psychologist, social worker, and/or nurse. Establishment of this type of group could be seen as addressing both intervention and prevention with this population. Furthermore, this type of approach would be an impetus to moving away from a purely medical model where only the chronically ill child is considered a focus for treatment, towards a social or ecological framework where the entire family unit of a chronically ill child is taken into consideration.

On the basis of the findings described and discussed above, it also seems necessary to provide physicians, nurses, and any other medical personnel who come into contact with the ill child and his/her family with parents' feedback. Green (1982) advocates a role for pediatricians in relation to the psychosocial aspects of child and family life and attempts to define that role. While this appears to be a step in the right direction, training to deal with the potential psychosocial effects of illness on the family is also recommended so that medical services could become more holistic. Parents should be given more encouragement

to join support groups and, in turn, these groups should be designed to better meet the needs of families of ill children. Public education is also imperative in order to combat the naivité and attitudes of the general population to chronic illness.

Semi-Structured Interview

The data emanating from the semi-structured interview proved to be very valuable because it provided a somewhat different picture of the siblings of children with chronic medical illnesses than emerged from the more formalized and standardized part of this research project. Siblings' self-ratings of their emotional adjustment suggested few significant differences from the control group and might lead one to suspect that the experience of living with a chronically ill sister/brother has little impact on affective functioning. That this is definitely not the case was made clear in the semi-structured interview. Most siblings interviewed indicated that the experience of having a sick brother/sister was a critical one for them. Though some siblings appeared to be coping with this situation very well and most seemed to be leading fairly "normal" lives, there was no question that this group of siblings encountered issues and conflicts in an ongoing way directly related to the chronic illness. The need for a broader perspective with pediatric chronic illness, i.e., an ecological or social one, thus received further endorsement.

Although similarities among siblings of children with all illnesses studied were found in the semi-structured interview, differences between and among illness subgroups were also observed suggesting the need to

adopt both a homogeneous as well as a specificity conceptualization of chronic illness in children. As will be seen in the discussion that follows and was alluded to in earlier parts of this paper, neither conceptualization alone is adequate. It seems that only in combination can a comprehensive understanding of the psychosocial impact of pediatric chronic illness be achieved. Furthermore, responses to some of the semi-structured interview questions suggested that at times an individualized approach to siblings may also be required.

In the subsequent section the semi-structured interview will be discusssed in the same order in which it was presented in the previous chapter. Implications for prevention and intervention with siblings of chronically ill children will also be addressed.

Knowledge of Chronic Illness

It seems necessary not to assume that the age of the well sibling is an indication of his/her knowledge of the illness. In this study, some very young siblings possessed a relatively sophisticated comprehension of the illness, whereas some older children had a very limited understanding of the disease and its implications. Although in some cases it was clear that parents had not given an adequate explanation, in other cases siblings seem to have communicated the message that they were not interested in being given any more information than they already had. Hence, a more individualized approach seems important when attempting to educate the family members, especially siblings of a chronically ill child.

Though the literature on communication in families with an ill child contains a debate about whether or not to inform well children in the

family about illness (Share, 1972), the issue does not seem to be as clear cut as this. What seems more relevant is that parents should be willing to discuss the illness, its management, and its implications with the healthy children in the family and that they should verbally and repetitively communicate this willingness to the siblings of the sick child. If and when a sibling does have an interest in receiving more information, an outlet for obtaining this would be available.

Perceptions of Impact of the Illness on the Afflicted Child

One area where a more homogeneous approach probably can be taken is with respect to how siblings perceive the impact of the illness experience on their brother/sister. In this study, regardless of the illness group, most siblings stated that they felt that their sister/brother had changed with the disease. An interesting age difference was identified however. Siblings who were quite young tended to point out the negative effects of these changes. What seemed to bother them most were the repercussions of the changes for themselves. They measured change in terms of what they lost, e.g., attention from parents, significant others, or a playmate. Older siblings, on the other hand, were much less egocentric in their responses. They seemed to be attempting to rationalize or intellectualize the changes that occurred and seemed less emotionally bruised by any negative implication of the changes for themselves. Therefore, younger siblings whose cognitive processes are less well developed may be more prone to feel hurt and confused by the changes they perceive and more likely to misinterpret the reasons for such changes. As a consequence, young siblings of children with

any type of chronic illness may require more of an explanation than older siblings of the changes occurring in the ill child's personal functioning and/or the way this child is treated by her/his parents. It is also very likely that parents need to be educated about the potential reactions of their healthy children to changes in the ill child and how they can deal with them if they are to prevent more adverse effects on emotional adjustment from occurring.

Effects on the Family

There were certain uniformities in siblings' from all three illness subgroups perceptions of the effects of the illness on the family. All siblings agreed that their parents often worried about the ill child's medical status and many gave the impression that they were very aware of the nature of their parents' concerns and the emotional burden this created for them. Supporting Taylor's (1980) findings, differences between siblings in the illness subgroups were evident in terms of who in the family was identified as most responsible for the care of the ill child and who had to sacrifice the most for this child. Furthermore, the majority of siblings were also very attuned to either or both of their parents involvement with the sick child. Most were able to recite a long list of things their parents did for the sick child on a daily basis and made remarks which suggested that they often resented the intensive devotion of time parents gave to this child. Validation for this observation comes from the finding that siblings most frequently identified themselves as being the member of the family who was most disturbed and unhappy because of the ill child's condition and its effects.

These findings lend credence to and extend the work of Meyerowitz and Kaplan (1967) and Crain, Sussman and Weil (1966) who present evidence indicating that the parent-sick child pattern of interactions is readjusted in families where there is a child with Cystic Fibrosis or Diabetes, respectively. Both report an intensification of the relationship between parents, particularly mother, and the ill child. The results of this portion of the interview also contribute sustenance to Crain and colleagues (1966) and Poznanski's (1969) contention that the "normal" sibling(s) in families with a chronically ill child is "handicapped" in the race for growth, attention, and affection. Moreover, they strongly indicate a need to help siblings of chronically ill children work through the feelings they may possess about the state of affairs in their family and, again, to educate parents about the potential reactions of their healthy children. The data presented previously which described the fact that many parents of sick children felt that they did not spend a sufficient amount of time with their healthy children reveals that some parents are aware of their more intensive involvement with the chronically ill child. Many parents also impressed as if they felt guilty about the unequal amounts of time spent with their children. Perhaps then, parents are also in need of support and assistance in this respect. Intervention directed at openly discussing this issue with the whole family present may prove beneficial.

Surprisingly, even though most siblings concurred that their parents were very caught up in the life of the ill child in the family and that this was often difficult to cope with emotionally, over half of the siblings asserted that no problems had been created for their family as a consequence of the illness. Whether denial or socially desirable responding was in operation, this was especially true of the siblings of

children with JRA. Furthermore, when family problems were acknowledged, different types of problems were delineated by illness subgroups. Siblings of Diabetic children focused more on the practical implications of the illness for the whole family and not just the afflicted child, for example, restrictions on diet and vacations. In contrast, the siblings of children with Gastrointestinal disorders focused on the emotional burden created for family members by the illness, especially anxiety and worry.

What accounts for these differences? It may be that contrary to Pless and Roghmann (1971) and others like them who contend that the chronicity of a medical illness per se is more important than individual aspects of it, specific features of the disease do have different implications for family functioning. Though the three subgroups of illness included in this study had many similar characteristics, they did differ on certain dimensions such as stability of prognosis and degree of life threat they imposed. The unique features of each of the illnesses alone or in combination may have accounted for the differences observed. If this is a valid explanation, it may carry implications for strategies of intervention and/or prevention with families of chronically ill children. More specifically, it would suggest the need to tailor interventions in accord with a specific disease entity.

Additional support for the notion that specific features of the illness are important to consider when working with families of chronically ill children accrues from responses to the question about whether any family members had extra chores and responsibilities related to the existence of the chronic illness. Almost half of the entire index group pointed to themselves as the family member who was given extra work

which they felt actually belonged to the ill child. Many siblings also indicated that they resented that they had more domestic chores than the child who was sick and that they were frequently asked to assist their sister/brother with some activity. Simeonsson and McHale (1981), in reviewing the research on sibling relationships in families with a handicapped child, cite several studies in the mental retardation field which report similar responses on the part of healthy siblings. More to the point however, in the current investigation a much larger proportion of the siblings of children with Diabetes, when compared to the other illness groups, stated that this was the case in their families.

One very plausible explanation for this is that due to the ongoing and relatively stable nature of Diabetes, the extra chores and responsibilities imposed on the siblings of children afflicted with this disease are never removed. Thus, they are more aware, stressed, and frustrated by them. On the other hand, the siblings of children with diseases characterized by remissions and exacerbations may have demands placed on them when the disease flares up, but may also be free of these extra responsibilities when the disease abates.

Impact on Well Siblings

The significance of the specific characteristics of a chronic illness was resonated in the questions that directly probed the impact of the illness experience on the siblings. Siblings of children with Diabetes much more frequently asserted that their sick brother/sister was the recipient of "special" treatment in the form of attention and/or material items from parents, grandparents, and others. Furthermore,

they were quite confident in their replies, expressing no ambivalence about this over the course of the two interviews. In contrast, the siblings of children with JRA and Gastrointestinal problems expressed much less certainty about their answer to this question and many gave different replies at each interview. Again, the difference in stability of prognosis between Diabetes and the other two illnesses seems the likely explanation for this finding. The differences may also be accounted for by the more obvious and pervasive daily treatment and living implications of Diabetes when compared to JRA and Gastrointestinal diseases. The dietary modifications, insulin injections, urine and blood testing, and exercise routines necessary every day for a child with Diabetes seem to impose themselves more apparently on the family and may require more time from parents than pills, baths, activity restrictions, or other daily requirements for children with the other illnesses studied.

Given the preceding, it was not unexpected to find that more siblings of children with Diabetes admitted feelings of jealousy towards their ill brother/sister than the other siblings who participated in the study. Age of the sibling acted as a moderator variable across all three illness subgroups in this regard however. Older children articulated more difficulty coping with the added attention given to the ill child and younger children expressed more problems handling what they perceived as material inequalities between themselves and the ill child.

When queried about their relationship with the sick child more homogeneity in the responses of siblings in the three groups was manifest. Almost two-thirds of the siblings interviewed admitted that their sister/brother was hard to get along with and attributed this to the illness. However, the need for caution in generalizing too much across

type of illness was raised again by virtue of the fact that fewer siblings of children afflicted with JRA admitted to this. Why they stood out from siblings in the other two illness subgroups was not clear.

What was clear was that the siblings of children with JRA were much more likely than siblings from the other two illness subgroups to focus on negative effects when they were asked how their sister's/brother's illness had affected their life. Though able to identify some positive effects, many more siblings of children with Diabetes gave answers which included a balance of both the pros and cons of their experience. In contrast, the majority of siblings of children with Gastrointestinal disorders offered answers suggestive of the positive consequences associated with being the sibling of a chronically ill child or alleged that their life had not been affected in any way.

Although, as indicated earlier, siblings in the three illness subgroups studied did not differ significantly from each other on the variable of age, siblings of children with JRA were the youngest ($\bar{x}$ = 11 years, 9 months) while siblings of children with Gastrointestinal disorders were the oldest ($\bar{x}$ = 13 years, 9 months). Thus, two full years separated the siblings. It seems quite credible to this researcher that, to some degree, age accounts for the discrepant findings reported with respect to this question. The older siblings, i.e., those of Gastrointestinal patients, might therefore have had more insight into and a better understanding of the effects of the illness and been more able and/or willing to overlook negative effects. Concomitantly, with their less egocentric and more mature cognitive processes they may have been able to recognize positive effects and make the best of the situation. Support for this explanation comes from Grossman (1972) who

interviewed adolescent and college-aged siblings of retarded children and judged that almost half (45%) had benefitted from their experience. Benefits similar to those voiced by the adolescent siblings in this study were reported, including an increase in altruistic concerns and tolerance toward other persons.

That many siblings do find their chronically ill sister/brother hard to get along with is evident. Likewise, that age was an important variable in this regard was clear. However, though age is a necessary explanation, it is not a sufficient one. In all three illness subgroups there were both adolescent aged and younger siblings, but their responses were not entirely predictable on the basis of this dimension. Some of the older siblings interviewed were noticeably embittered and frustrated by their experience, while some of the younger siblings were not. The question that therefore arises is what else differentiates the siblings of children with Gastrointestinal disorders from the siblings of children with the other illnesses? Perhaps the answer to this question lies in some other unique feature of Gastrointestinal disorders. Future research with a larger sample of subjects within each illness subgroup may need to address this issue. Furthermore, subsequent studies should consider administering a semi-structured interview not only to index subjects but to those in the control group as well. Although the siblings of chronically ill children who participated in this study acknowledged experiencing much anger, jealousy, and conflict in their relationship with their ill brother/sister, these behaviors and feelings may be natural occurrences in all families.

At this point, it should be apparent that, while there was homogeneity in some of the responses of the siblings of children from the

three medical illnesses studied, there was also heterogeneity in responses. Where the latter was evident, consideration of the specific characteristics of the illness helped account for siblings' replies. The age of siblings was also a relevant variable which assisted in the comprehension of the impact of the illness experience on siblings of children with chronic diseases. At times though, it was difficult to attain an understanding of the data through its categorization into the broad classification of chronicity, or the more narrow conception of specific types of illness, or even age of respondent. It was here that the role of individual differences among siblings and their families that were otherwise blurred by group averages came into play. Nowhere was this more lucid than on the final question of the semi-structured interview.

Every sibling interviewed had advice to offer to other children who had a chronically ill sister/brother. Some common themes were expressed in the advice of siblings including a caution to be prepared for feelings of exclusion and that the ill child should not be allowed to take advantage of his/her illness. The need to be more responsible and considerate was raised by several siblings. There was also a strong suggestion by a few siblings that the first year was most difficult and that life improved with the passage of time. Both positive and negative aspects of the experience were conveyed and marked individual differences in length of reply to this question, tone of response, quality of affect displayed, and interest demonstrated in talking about their experience were observed. There were occasions where interviews lasted two and a half to three hours because a sibling was so eager to talk to someone about this aspect of his/her life. One sibling informed this researcher in a very resentful tone of voice, that nobody had ever expressed interest

in discussing the illness experience with her before, despite the fact that her life was directly affected by the situation. Another sibling spontaneously stated, during his reply to this question, that he thought that the semi-structured interview was better than the formal part of the study because it allowed him to think and talk about a very important part of his life. Directly opposed to this, two siblings were very curt and abrupt in their responses and very firmly insisted that nothing had changed for them in the time their brother/sister had been ill. Tears were streaming down one girl's face as she made this statement. Other siblings also shed tears during this part of the interview and one even confessed what she labelled a "well kept secret" from her family that in part pertained to her feelings about having a chronically ill brother. Regardless of the similarities in responses uttered, every sibling's experience was unique and each one seemed to be coping with it in her/his own way.

SUMMARY AND CONCLUSIONS

In conducting research with siblings of chronically ill children it is important to employ both standardized measuring instruments as well as a less structured, open-ended interview. The latter affords one the opportunity to achieve a more complete picture of the day-to-day experiences of living with a chronically ill sister/brother for siblings and provides valuable information not available from forced-choice standardized measures.

The inclusion of a temporal dimension to the study of this population has also proven to be enlightening and should be continued in future research. The longitudinal design allows examination of the stability or instability of effects over time and can lead to a more reliable and accurate understanding of the psychosocial impact of the chronic illness experience. It also takes into account an appreciation of the developmental process of living with a chronically ill child.

In the present investigation, the findings of the formal assessment of the siblings of chronically ill children taken together with the data which emanated from the semi-structured interview revealed the potential of the illness experience to have both positive and negative effects on the psychosocial adaptation of siblings, and for some of these effects to remain stable over time while others varied with the passage of time. The majority of siblings had some information about their brother's/sister's illness, perceived effects on their parents and the ill child, and identified some impact of the illness experience on their daily life and

personal functioning. The most significant difference between siblings of chronically ill children and those in the control group was evidenced in the behavioral sphere of functioning, especially in their increased incidence of shy-anxious behavior. This finding was stable over time. Some differences in anxiety level were also apparent but were less consistent. There was a suggestion that siblings of ill children may be able to cope better than controls with the stress engendered by novel situations. No differences between groups were revealed in terms of self-concept.

The need to study variables that may moderate the adjustment of siblings of chronically ill children was also indicated. The important role played by family variables was highlighted in this regard. Furthermore, the data strongly suggested that certain features of an illness, i.e., its stability of prognosis, may be connected to the impact the illness experience has on siblings. Though age was not statistically verified as a moderating variable, qualitatively different responses to many of the open-ended questions were given by younger as opposed to older siblings.

What are some of the implications of these findings? Parents need to be educated about the potential effects on siblings of living with a chronically ill sister/brother and of how their involvement with the ill child affects their well children. It is essential to provide them with strategies and support for preventing adverse consequences or, conversely, for fostering positive adaptation. Routine assessment of how the family is coping should be part of all treatment plans made by the physician and/or multidisciplinary team working with the ill child and his/her family. This implies a move away from the traditional medical

model to a more social-ecological framework.

Where maladjustment is already in existence, interventions should be available and implemented. In contrast to the literature which precedes this investigation and recommends that only the parents of chronically ill children and the child who is sick require support and guidance, the present study's findings suggest that the healthy siblings in these families equally merit these services. They also carry the burden of illness but, unfortunately, to date have received little attention from both the medical and mental health community.

In view of the eagerness of many siblings who participated in this study to talk about their experiences and feelings related to having a brother/sister with a long-term medical condition, one vehicle for meeting the needs of siblings is a sibling group. Two such groups have been described (Chinitz, 1981; Cunningham, Betsa, and Gross, 1981). Both were short-term and had as their primary objectives the provision of support and information. No formal systematic evaluation took place, but the groups were viewed as successful in helping siblings define and discuss common problems. The group experience may also provide an environment that is conducive to the exploration of the educational and psychological needs of siblings of children with chronic illnesses and an opportunity to improve their quality of life.

Though more investigations of a rigorous nature with longitudinal designs and refined measures are required to confirm the findings of this study on the psychosocial adaptation of siblings of chronically ill children, the time has come to act on the data that is currently available.

Reference Notes

1. Siemens, C. Personal communication, August 1981.

2. Paykel, E. S. Life events and acute depression. Paper presented at Annual Meeting of the American Association for the Advancement of Science. Chicago, December 1970.

3. Pless, I. B. Effects of chronic illness on adjustment: Clinical implications. Paper presented at Behavioral Pediatrics Conference. Ottawa, Canada, May 1982.

4. Tritt, S. F. Sibling adjustment of families with institutionalized mentally retarded children: A controlled study. Unpublished Manuscript, 1980.

5. Quay, H. C., & Peterson, D. R. Manual for the Behavior Problem Checklist. Unpublished Manuscript, 1975.

6. Nelson, G. B. Families coping with loss of father by death or divorce. Unpublished Manuscript, 1979.

7. Spinner, B. Personal communication, May 1980.

8. Lind, J. Personal communication, November 1982.

References

Achenbach, T. M. The child behavior profile: An empirically based system for assessing children's behavioral problems and competencies. International Journal of Mental Health, 1979, 7, 24-42.

Ackerman, N. W. The psychodynamics of family life: Diagnosis and treatment of family relationships. New York: Basic Books, 1958.

Adams, D. W. Childhood malignancy: The psychosocial care of the child and his family. Illinois: Charles C. Thomas, 1979.

Anthony, E. J. A Working model for family studies. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Beavers, W. Psychotherapy and growth: A family systems perspective. New York: Bruner-Mazel, 1977.

Begleiter, M. L., Burry, B. F., & Harris, D. J. Prevalence of divorce among parents of children with cystic fibrosis and other chronic disease. Social Biology, 1976, 23 (3), 260-264.

Binger, C. M. Childhood leukemia - Emotional impact on siblings. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Binger, C. M., Ablin A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. Childhood leukemia: Emotional impact on patient and family. New England Journal of Medicine, 1969, 280 (8), 414-418.

Bledsoe, J. C. Sex and grade differences in children's manifest anxiety. Psychological Reports, 1973, 32, 285-286.

Blishen, B. R. A socio-economic index for occupations in Canada. Canadian Review of Sociology & Anthropology, 1967, 4, 41-53.

Bolstad, C. A behavioral comparison of handicapped and normal children within the family. Dissertation Abstracts International, 1974, 35, 4160.

Bowen, M. The use of family theory in clinical practice. Comprehensive Psychiatry, 1966, 7, 345-374.

Brewer, E. J. Jr., Juvenile rheumatoid arthritis. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Cain, A. C., Fast, I., & Erickson, M. E. Children's disturbed reaction to the death of a sibling. American Journal of Orthopsychiatry, 1964, 34, 741-752.

Cairns, N. V., Clark, G. M., Smith, S. D., & Lansky, S. B. Adaptation of siblings to childhood malignancy. Journal of Pediatrics, 1979, 95 (3), 484-487.

Caplan, G. Support systems and community mental health. New York: Behavioral Publications, 1974.

Castaneda, A., McCandless, B. R., & Palmero, D. S. The children's form of the Manifest Anxiety Scale. Child Development, 1956, 27, 316-317.

Chinitz, S. P. A sibling group for brothers and sisters of handicapped children. Children Today, 1981, Nov-Dec., 21-23.

Coddington, R. D. The significance of life events as etiologic factors in the diseases of children I. A survey of professional workers. Journal of Psychosomatic Research, 1972, 16, 7-18 (a).

Coddington, R. D. The significance of life events as etiologic factors in the diseases of children II. A study of a normal population. Journal of Psychosomatic Research, 1972, 16, 205-213 (b).

Cook, T., & Campbell, D. Quasi-experimental design and analysis issues for field settings. Chicago: Rand McNally College Publishing Co., 1979.

Cotter, J. M., & Schwartz, A. D. Psychological and social support of the patient and family. Major Problems in Clinical Pediatrics, 1978, 18, 120-127.

Crain, A. J., Sussman, M. B., & Weil, W. B. Family interaction, diabetes, and sibling relationships. International Journal of Social Psychiatry, 1966, 12, 35-43.

Cunningham, C., Betsa, N., & Gross, S. Sibling groups: Interaction with siblings of oncology patients. American Journal of Pediatric Hematology/Oncology, 1981, 3 (2), 135-139.

Cytryn, L., Moore, P., and Robinson, M. E. Psychological adjustment of children with cystic fibrosis. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: Impact of disease and death. New York: John Wiley & Sons, 1973.

Davis, F. Passage through crisis: Polio victims and their families. New York: Bobbs-Merrill, 1963.

Davis, R. E. Family of physically disabled child. New York State Journal of Medicine, 1975, 95, 1039-1041.

Dunlap, W. R., & Hollinsworth, J. S. How does a handicapped child affect the family? Implications for practitioners. Family Coordinator, 1977, 26 (3), 250-263.

Eiser, C. Psychological development of the child with leukemia: A review. Journal of Behavioral Medicine, 1979, 2 (2), 141-157.

Farber, B. Effects of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 1959, 24 (2), 1.

Farber, B. Family organization and crisis: Maintenance of integration in families with a severely mentally retarded child. Monographs of the Society for Research in Child Development, 1960, 25 (1), 1.

Finch, A. J., Montgomery, L. E., & Deardorff, P. A. Children's Manifest Anxiety Scale: Reliability with emotionally disturbed children. Psychological Reports, 1974, 34, 658.

Framo, J. L. Symptoms from a family transactional viewpoint. International Psychiatry Clinics, 1970, 7, 125-171.

French, A. Disturbed children and their families. New York: Human Sciences Press, 1977.

Friedman, S. B. General Discussion. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Frith, S. & Narikawa, D. Measures of self-concept K-12, Revised Edition. Los Angeles: Instructional Objectives Exchange, 1972.

Froom, J. Prevalence and natural history of chronic diseases in childhood. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U. S. Department of Health, Education, and Welfare: Public Health Service, NIH, 1976.

Gath, A. The school age siblings of mongol children. British Journal of Psychiatry, 1973, 132, 161-167.

Gayton, W. F., Friedman, S. B., Tavormina, J. F., & Tucker, F. Children with Cystic Fibrosis: 1. Psychological test findings of patients, siblings, and parents. Pediatrics, 1977, 59 (6), 888-894.

Golan, N. Treatment in crisis situations. New York: The Free Press, 1978.

Gordon, N. B., & Kutner, B. Long term and fatal illness and the family. Journal of Health and Human Behavior, 1965, 6, (4), 190-196.

Grave, G. D. The impact of chronic childhood illness on sibling development. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Green, M. Pediatrics and the psychosocial aspects of child and family health. Pediatrics, 1982, 79 (1), 126-127.

Green, M., & Haggerty, R. J. Introduction. Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968 (a).

Green, M., & Haggerty, R. J. Epidemiology of chronic disease. Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968 (b).

Grossman, F. K. Brothers and sisters of retarded children. Syracuse: Syracuse University Press, 1972.

Haley, J. Research on family patterns: An instrument measure. Family Process, 1967, 6, 81-97.

Hamovitch, M. B. The parent and the fatally ill child. City of Hope Medical Center, Duarte, California, 1964.

Hawke, W. A. Impact of cerebral palsy on patient and family. Canadian Nurse, 1967, 63 (1), 29-31. (Abstract)

Heffron, W. A., Bommelaere, K., & Masters, R. Group discussions with parents of leukemic children. Pediatrics, 1973, 52 (6), 831-839.

Holmes, T. H., & Rahe, R. H. The social readjustment rating scale. Journal of Psychosomatic Research, 1967, 11, 213-218.

Hymovich, D. P. A framework for measuring outcomes of intervention with the chronically ill child and his family. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education, and Welfare: Public Health Service, NIH, 1976.

Illingworth, R. S. The increasing challenge of handicapped children. Clinical Pediatrics, 1964, 3, 189-191.

Kaplan, D. M., Smith, A., Grobstein, R., & Fischman, S. E. Family mediation of stress. Social Work, 1973, 18 (4), 60-69.

Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J., Rigler, D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. Journal of Pediatrics, 1980, 97 (1), 126-131.

Kenny, D. A. A quasi-experimental approach to assessing treatment effects in the non-equivalent control group design. Psychological Bulletin, 1975, 82, (3), 345-362.

Kitano, H. L. Validity of the Children's Manifest Anxiety Scale and the modified revised California Inventory. Child Development, 1960, 31, 67-72.

Klein, S. D. Chronic kidney disease: Impact on the child and family and strategies for coping. (Doctoral dissertation, University of Minnesota, 1975). Dissertation Abstracts International, 1975, 36,(8).

Klein, S. D. Measuring the outcome of the impact of chronic illness in childhood on the family. In G. D. Grave & I. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Korsch, B. M. Outcome data for chronic renal patients. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Korsch, B. M., Negrette, V. F., Gardner, J. E., Weinstock, C. L., Mercer, A. S., Grushkin, C. M., & Fine, R. W. Kidney transplantation in children: Psychosocial follow up study on child and family. Journal of Pediatrics, 1973, 83, (3), 399-408.

Lansky, S. B., & Gendell, M. Symbiotic regressive behavior patterns in childhood malignancy. Clinical Pediatrics, 1978, 17, (2), 133-138.

Lansky, S. B., Cairns, N. V., Hassanein, R., Wehr, J., and Lowman, J. T. Childhood cancer: Parental discord and divorce. Pediatrics, 1978, 62 (2), 184-188.

Lavigne, J. V., & Ryan, M. Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 1979, 63 (4), 616-627.

Lawler, R. H., Nakielny, W., & Wright, N. A. Psychological implications of cystic fibrosis. Canadian Medical Association Journal, 1966, 94 1043-1046.

Leiken, S. J., & Hassakis, P. Psychological study of parents of children with cystic fibrosis. In E. J. Anthony and C. Koupernik (Eds.) The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Levin, S. Nephrotic syndrome in childhood. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Levine, S. General discussion on the impact of childhood chronic illness on sibling development. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health Education and Welfare: Public Health Service, NIH, 1976.

Levine. S. Sex role identification and parental perceptions of social competence. American Journal of Mental Deficiency, 1965-66, 70, 822-824.

Liberthson, E. Helping families live with and for the mentally retarded child. Journal of Rehabilitation, 1968, 34 (6), 21-26.

Linder, R. Mothers of disabled children: The value of weekly group meetings. Developmental Medicine and Child Neurology, 1970, 12, 202-206.

Lewis, M. Clinical aspects in child development (Chapter 17). Philadelphia: Lea & Febiger, 1982.

Lurie, P. R. Congenital and rheumatic heart disease. In M. Green & R. J. Haggerty (Eds.),Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Mattson, A. Long term physical illness in childhood: A challenge to psychosocial adaptation. In R. H. Moos (Ed.), Coping with physical illness. New York: Plenum, 1979.

Mattson, A., & Gross, S. Adaptational and defensive behavior in young hemophiliacs and their parents. American Journal of Psychiatry, 1966, 122, 1349-1356.

Mattson, J. The chronically ill child: A challenge to family adaptation. Medical College Virginia Quarterly, 1972, 8 (3), 171-175.

Mauer, A. M., Simone, J. V., & Pratt, C. B. Current progress in the treatment of the child with cancer. The Journal of Pediatrics, 1977, 91 (4), 523-539.

McAnarney, E., Pless, I. B., Satterwhite, B., & Friedman, S. B. Psychological problems of children with chronic juvenile arthritis. Pediatrics, 1974, 53, 523-530.

McCollum, A. T., & Gibson, L. E. Family adaptation to the child with cystic fibrosis. Journal of Pediatrics, 1970, 77 (4), 571-578.

Meyerowitz, J. H., & Kaplan, H. B. Familial response to stress: The case of cystic fibrosis. Social Science and Medicine, 1967, 1, 249-266.

Minde, K., Hackett, J., Killou, D., & Silver, S. How they grow up: 41 physically handicapped children and their families. American Journal of Psychiatry, 1972, 128 (12), 1554-1560.

Minuchin, S. Families and family therapy. Cambridge, Mass.: Harvard University Press, 1974.

Murstein, B. I. The effect of long-term illness of children on the emotional adjustment of parents. Child Development, 1960, 31, 157-171.

Newell, P. Measurement of outcome of chronic illness in children: The view from family practice. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare. Public Health Service, NIH, 1976.

Nie, N. H., Hull, C. H., Jenkins, J. G., Steinbrenner, K., & Bent, P. H. Statistical Package for the Social Sciences, U.S.A., 1975.

Oakley, G. P., & Patterson, R. B. The psychological management of leukemic children and their families. North Carolina Medical Journal, 1966, 4, 186-193.

Peck, B. Effects of childhood cancer on long-term survivors and their families. British Medical Journal, 1979, 1, 1327-1329.

Peterson, D. R. Behavior problems of middle childhood. Journal of Consulting Psychology, 1961, 25, 205-209.

Pfefferbaum, B. Pediatric oncology: A review of the changing psychological aspects. International Journal of Psychiatry in Medicine, 1978-79, 9 (3 & 4), 289-296.

Pilling, D. The child with a chronic medical problem - cardiac disorders, diabetes, hemophilia. National Children's Bureau Report. England: NFER Publishing Co., 1973.

Pless, I. B. The challenge of chronic illness. American Journal Diseases of Children. 1973, 126, 741-742.

Pless, I. B. Measurement of outcome: A review of the problem. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education, and Welfare, Public Health Service, NIH, 1976.

Pless, I. B., & Pinkerton, P. Chronic childhood disorder - Promoting patterns of adjustment. London: Henry Kimpton Publishers, 1975.

Pless, I. B., & Roghmann, K. J. Chronic illness and its consequences: Observations based on three epidemiologic surveys. The Journal of Pediatrics, 1971, 79 (3), 351-359.

Pless, I. B., & Satterwhite, B. A measure of family functioning and its application. Social Science and Medicine, 1973, 7, 613-621.

Pless, I. B., Roghmann, K., & Haggerty, R. J. Chronic illness, family functioning, and psychological adjustment: A model for the allocation of preventive mental health services. International Journal of Epidemiology, 1972, 1, 271-277.

Poznanski, E. Psychiatric difficulties in siblings of handicapped children. Clinical Pediatrics, 1969, 8 (4), 232-234.

Poznanski, E. Emotional issues in raising handicapped children. Rehabilitation Literature, 1973, 34 (11), 322-326.

Quay, H. C. Patterns of agression, withdrawal and immaturity. In H. C. Quay & J. S. Werry (Eds.), Psychopathological disorders of childhood. New York: John Wiley & Sons, 1972.

Quay, H. C. Measuring dimensions of deviant behavior: The Behavior Problem Checklist. Journal of Abnormal Child Psychology, 1977, 5 (3), 277-287.

Quay, H. C., & Quay, L. C. Behavior problems in early adolescence. Child Development, 1965, 36, 215-220.

Raimbault, G. Psychological problems in the chronic nephropathies of childhood. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Reynolds, C. R., & Richmond, B. O. What I Think and Feel: A revised measure of Children's Manifest Anxiety. Journal of Abnormal Child Psychology. 1978, 6 (2), 271-280.

Reynolds, C. R., & Richmond, B. O. Factor structure and construct validity of what I Think and Feel. Journal of Personality Assessment, 1979, 43 (3), 281-283.

Rhyne, M. B. Growing up as an atopic child. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Richardson, S. The effect of physical disability on the socialization of a child. In D. A. Goslin & D. C. Glass (Eds.), A handbook in socialization theory. New York: Rand McNally, 1968.

Robertson, S. Adolescents and dying. Medical Journal of Australia, 1978, 1 (8), 419-421.

Rosenthal, R., & Rosnow, R. L. The volunteer subject. In R. Rosenthal and R. L. Rosnow (Eds.), Artifact in behavioral research, New York: Academic Press, 1969.

Rutter, M., Tizard, J., & Whitmore, K. Education, health and behavior. London: Longmans, Green & Co., 1970.

Sarason, S. B., Davidson, K. S., Lighthall, F. F., Waite, R. R., & Ruebush, B. K. Anxiety in elementary school children. New York: Wiley, 1960.

Satir, V. The family as a treatment unit. In J. Haley (Ed.), Changing families. New York: Grune & Stratton, 1971.

Satterwhite, B., Zweig, S., Iker, H., & Pless, B. The Family Functioning Index - Five year test-retest reliability and implications for use. Journal of Comparative Family Studies, 1976, 7, 111-116.

Schiffer, C. G., & Hunt, E. P. Illness among children. Data from United States National Health Survey, Washington, D.C.: U.S. Government Printing Office, 1963.

Share, L. Family communication in the crisis of a child's fatal illness: A literature review and analysis. Omega, 1972, 3 (3), 187-201.

Sigal, J. J., Chigoya, L., Villeneuve, C., & Mayerovitch, J. Later psychosocial sequelae of early childhood illness (severe croup). American Journal of Psychiatry, 1973, 130 (7), 786-789.

Simeonsson, R. J., & McHale, S. M. Review: Research on handicapped children: Sibling relationships. Child Care Health and Development, 1981, 1, 153-171.

Swift, C., Seidman, F., & Stein, H. Adjustment problems in juvenile diabetes. Psychosomatic Medicine, 1967, 29 (6).

Taylor, S. C. The effect of chronic childhood illnesses upon well siblings. Maternal Child Nursing Journal, 1980 (Sum), 9 (2), 109-116.

Tew, B., & Laurence, K. Mothers, brothers, and sisters of patients with spina bifida. Developmental Medicine and Child Neurology, 1973, 29, 69-76 (Suppl. 29).

Tew, B., Laurence, K., Payne, H., & Rawnsley, K. Marital stability following the birth of a child with spina bifida. British Journal of Psychiatry, 1977, 131, 79-82.

Turk, J. Impact of cystic fibrosis on family functioning. Pediatrics, 1964, 34 (1), 67-71.

Vignos, P. J. Management of Duchenne progressive muscular dystrophy. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Weil, W. B. Diabetes mellitus. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Zeidel, A. Problems of emotional adjustment in juvenile diabetes. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. Psychological effects of illness in adolescence. II. Impact of illness in adolescents-crucial issues and coping styles. Journal of Pediatrics, 1980, 97 (1), 132-138.

APPENDICES

APPENDIX A

A LITERATURE REVIEW

APPENDIX A

PSYCHOSOCIAL ADJUSTMENT IN FAMILIES WITH A CHRONICALLY ILL CHILD

A LITERATURE REVIEW

Chronic illness has been defined as a condition which persists for more than three months (Green & Haggerty, 1968 a, b) and is characterized by a high intensity of intervention (Grave, 1976). Both social scientists and medical clinical investigators who have been involved in the study of chronic illness have observed that prolonged illness in children is a common source of stress that poses major problems of adjustment not only for the patient but also for other family members and for the family as a whole unit (French, 1977; Kaplan, Smith, Grobstein & Fischman, 1973). Labelled a serious crisis experience, important implications for personality functioning, the familial role system, the relationship between the family unit and society at large, as well as for the interaction between these systems are noted by representatives of the various disciplines who have studied families wherein there is a chronically ill youngster.

In spite of the fact that contemporary clinicians and researchers (e.g., Minuchin, 1974) are beginning to examine the family system, the literature discussing chronic illness in children focuses predominantly on the stresses imposed on and adaptations made by the patient and his/her parents. Findings relating to the adjustment of both of these

family members have been reported in relationship to numerous specific disease entities including leukemia, hemophilia, cystic fibrosis, polio, nephrosis, muscular dystrophy, diabetes, mental illness, congenital heart disease, asthma and rheumatoid arthritis (Pfefferbaum, 1978-79; Mattson & Gross, 1965; McCollum & Gibson, 1970; Davis, 1963; Levin, 1970; Vignos, 1968; Weil, 1968; Poznanski, 1969; Lurie, 1968; Rhyne, 1970; Brewer, 1968). Although both crisis theory and systems theory argue for the potential development of unique and often positively adaptive responses to stress and challenge, the studies conducted to date are quite pathology oriented and their findings support the negative effects of the illness experience on the ill child and the parents of this child.

In contrast to the sharp awareness of the complex reactions and adjustments of the parents and ill child, the healthy siblings in such families have been largely ignored. Though few in number, the most methodologically sophisticated studies have reported significant maladjustment in behavioral development among siblings of mentally retarded children (Farber, 1959; 1960; Gath, 1973; Tritt, Note 1) and those with physical disabilities (Tew & Laurence, 1973). A significantly increased incidence of emotional maladjustment particularly with regard to family relationships was also found by Tritt, (Note 1) in siblings of retarded children.

What about the healthy children in families where there exists a youngster with diabetes, cystic fibrosis, cancer, hemophilia or another long term "medical" illness? In view of the evidence linking the presence of a chronic disease with maladaptive psychological reactions in the child-patient and parents, disrupted marital relationships (Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978; Tew, Laurence, Payne &

Rawnsley, 1977) and disequilibrium in family functioning (Futterman & Hoffman, 1973; Meyerowitz & Kaplan, 1967), serious consideration of the impact of any one of these long term diseases on healthy siblings must occur. Yet, there have been only a couple of attempts to deal with this issue in a systematic fashion and no longitudinal studies have been carried out on this population. The majority of available information derives from retrospective anecdotal accounts, interview data, parental reports, or very small scale uncontrolled studies where the effects of numerous potentially confounding variables have not been ruled out. Thus, methodological shortcomings pervade this small literature. Furthermore, ambiguity about the influence of such variables as the characteristics of the illness and of the sibling on adjustment exists.

In view of these problems, there is clearly a need to more rigorously examine this sibling population. However, prior to undertaking such an endeavor, a review of the research on the adaptation of the child patient and her/his parents, family functioning, and of the preliminary evidence on sibling adjustment is necessary in order to clarify the direction future research should take.

Information about the epidemiology and social context of childhood chronic illness will be presented before reviewing this literature as it provides a necessary backdrop to comprehending the effects of the illness experience.

EPIDEMIOLOGY OF CHILDHOOD CHRONIC ILLNESS

Epidemiological studies of the frequency of chronic illness in childhood have revealed total prevalence rates ranging from 57 to 281 per 1000 children (Pless, 1968). While some of the explanation for this variation in rates reflects the different methodological techniques employed by researchers, it is equally likely that the reluctance, until recently, to look at chronic conditions as entities which have much in common is responsible. Due to this hesitation, much of the information available on the prevalence of chronic disease in children has dealt with individual disorders and, to complete the picture, data from diverse sources have had to be synthesized arbitrarily.

Although the trend is changing such that it is now more common for investigators to consider disorders as biologically diverse as diabetes, asthma, and nephrosis as a homogeneous group by virtue of their chronicity and fundamental differences from the more frequent acute illnesses of childhood (Korsch & Barnett, 1961; Korsch, Negrette, Gardner, Weinstock, Mercer, Grushkin & Fine, 1973; Pless, 1973; Solnit, 1973), there are few surveys restricted to morbidity in childhood and still fewer which deal exclusively with chronic illnesses. A number of large scale sampling surveys have, however, included data on children while obtaining morbidity figures for a community or nation.

Surveys of General Morbidity at any Age

Keller (1953) and Logan and Cushion (1958) both collected morbidity

data on children as part of their larger surveys on the adult population. They report quite disparate figures, ranging from 138 to 185 children per 1000 who experienced one or more chronic illnesses. According to Pless and Douglas (1971), the variation in reported prevalence amongst these studies is a result of the widely differing definitions of chronic illness employed and the almost exclusive use of sampling and cross-sectional methods as opposed to longitudinal population studies. Another methodological consideration which may account for the discrepancy in reported rate amongst these three studies pertains to their methods of data collection.

According to Pless (1968), in evaluating the results of any study, it is important to know (1) whether the information originated from records, or directly from a prospective case or his/her near relatives; (2) whether examinations with or without special tests were given to some or all of the persons studied; (3) the reliability and the validity of the data and how these have been assessed; and (4) the grading of the disorders according to severity in terms of their personal or social consequences and their duration.

Surveys of General Morbidity in Childhood

This type of survey focuses on both acute and chronic illness in childhood populations. Although a number of such surveys have been conducted and these reports could constitute an excellent source of morbidity data, they fail to do so because insufficient attention has been given to standardizing the surveys used. As a result, extremely large variations are reported for many conditions and the validity of these statistics are very questionable. An extreme example is seen in

the case of "heart conditions" in which rates varying from 1.55 to 50.77 per 1000 are given, depending on the local authority involved and method of data collection employed. Due to this unfortunate state of affairs, there is no rationale for reporting figures at this time.

Surveys Restricted to Chronic Conditions in Childhood

The three most rigorous and methodologically sophisticated studies of chronic diseases exclusive to childhood are summarized by Pless and Roghmann (1971). All three studies deal with multiple chronic disorders and overcome some of the methodological flaws which characterize the previous surveys described. In this sense then, these three studies are a more valid and reliable estimate of prevalence. The National Survey of Child Health and Development (Schiffer & Hunt, 1963) was of a longitudinal cohort design. The Isle of Wight study (Rutter, Tizard and Whitmore, 1970) which surveyed the total population of 9 to 11 year old children on the Isle of Wight, and the Rochester Child Health Survey (Pless, Roghmann & Haggerty, 1972) which consisted of a 1 per cent probability sample of all children under 18 living in Monroe County, New York were cross-sectional. Each of these studies reports chronicity rates of 11%, 6%, and 12% respectively.

Both the National Survey of Health and Development and the Rochester Child Health Survey permitted a comparison of the chronically sick children and a random sample of healthy children. The only demographic characteristic found to distinguish between the groups was the higher rate of boys among the chronically ill.

How permanent were these disorders? A judgement regarding actual and expected duration of the conditions was made in the National Survey

as it was a longitudinal study. On the basis of its findings, Pless and Roghmann (1971) state that it is reasonable to conclude that at least one third and probably more of the chronic illnesses of childhood are likely to be permanent.

Ratings of severity of the illness, determined by the extent to which the condition interfered with the child's usual daily activities, were attained in all three studies. Although their definitions were not completely comparable, the results indicated that 37-53% of the cases were rated "mild" in that the condition interfered only with strenuous activities. One third to one half of the members of the three groups had "moderately" severe conditions such that they were unable to participate in usual daily activities. The remaining 12 to 13% of the disabilities were "severe", confining the child to bed.

In spite of the variation in rates reported in the three types of studies described above, there appears to be general agreement that the total prevalence of chronic conditions in most populations under 18 lies between 10 and 15% depending on how broad a definition of chronic disease is used and on the methods employed for identification. Illingworth (1964) suggests that this rate is increasing in most countries in which there are advanced systems of medical care. He observes that medical technology is increasing the survival of many children with congenital malformations and other disorders who, in the past, would have died. The improved prognosis for cystic fibrosis patients (McCollum & Gibson, 1970) and for children with cancer (Mauer, Simone & Pratt, 1977) supports this contention. Clearly then, chronic childhood illness affects a rather large and significant proportion of the child population.

SOCIAL CONTEXT OF CHILDHOOD CHRONIC ILLNESS

When a family member develops a chronic illness, the family's self image will change from one more or less like other families to one that has been singled out for misfortune. Furthermore, being afflicted with a chronically ill member, looms for the family as a discriminating barrier in the attainment of important social values (Davis, 1963).

Though chronic illness in a child usually elicits more sympathetic responses from society at large as well as the medical community than chronic illness in an adult, many of the basic problems with which families of chronically ill children have to contend with come directly from societal and medical attitudes.

Research confirms that mentally and physically ill persons are subject to group stereotypes. Non-disabled persons tend to treat them as if they are disabled in every way (English, 1971). Moreover, the media frequently displays the disabled person as a dependent individual requiring special services and support from the community in order to function adequately (Gardner & Radel, 1978). Constant exposure to such descriptions maintains and reinforces the stable negative attitudes that the general population possesses about the physically and mentally disabled (Harasymis, Horne & Lewis, 1976). Children even appear to be influenced by these stereotypes. They are less inclined to initiate social relations with a disabled child than a non-disabled child and have more positive feelings about children who have no visible disability than those whose appearance is affected by their illness (Richardson, 1970).

Greer (Note 2) asserts that societal attitudes and stereotypes are strong contributors to the feelings of guilt and failure that most parents of ill children have. Although primarily referring to families in which there is a mentally retarded child, he points out that these parents are made to feel that they have not lived up to the ideal of producing a "perfect" child and that society then hypocritically says they must be "superparents". Many of these same feelings and experiences are reported by parents of children with chronic medical illnesses and it thus seems that there is some overlap in the lives of parents of children with a variety of chronic disorders.

There is, however, one way in which type of chronic illness makes a difference. In contrast to the general public's awareness of some of the hardships and experiences that families with a retarded child may encounter, general ignorance regarding the impact of chronic medical illnesses upon the daily fabric of family life prevails. It seems as if only those medical diseases which are in the public eye through charity campaigns (e.g., cancer, muscular dystrophy) are known to the average lay person who himself/herself has not had a personal experience with a chronically ill youngster. Public education about other medical illnesses is an infrequent occurrence. Hence, families in which there is a child with a chronic medical illness may receive even less support and understanding from society than families in which there is a retarded child member.

In contrast to the lack of emphasis on the public response to chronic illness, attention has recently turned toward the response of the medical community to chronically ill children. Ford, Liske and Ort (1962) noted that physicians and medical students react negatively

to patients with chronic illness. They observed a reluctance on the part of doctors and students to participate in the care of such patients especially after the diagnostic phase. O'Hara (1977) and Steele (1977) point out that rewards are not obtained as readily with patients who have long term disorders and that the goals for treatment of such conditions are different from those for acute illnesses (palliative versus cure). Since cure is not yet possible, many medical personnel dealing with chronic populations experience feelings of frustration and inadequacy in their roles (Steele). One can only attempt to imagine to what degree these feelings are amplified when the patient is a child and the disorder is life-threatening.

Teyber and Littlehales (1981) addressed the issue of staff reactions to childhood illness and found that staff typically used one of two ways to cope with their emotional reactions to being with children beseiged with chronic illness. They documented initial overinvolvement with the ill child especially by less experienced workers, followed by the more common response pattern of becoming colder, more uninvolved and "professional". They conclude that neither of these methods of coping works very well and that there is a profound unmet need for medical personnel to have a setting where they can talk about the feelings aroused in their work.

The implementation of support services for medical personnel together with the recent advances made in prolonging the life of children with various chronic illnesses may provide optimism and enchanced rewards for the medical staff caring for children with long-term disorders. Increased survival and cure have not been without costs, however. Medication, surgery, and intensive therapeutic regimes have left many children

with physical and emotional scars.

It seems that not until these scars on the patient as well as their effects on the family receive routine attention and the public is better educated will the social context of chronic illness be conducive to growth.

PSYCHOSOCIAL ADJUSTMENT OF FAMILIES OF CHRONICALLY ILL CHILDREN

Although an abundance of reports are available pertaining to psychosocial adjustment, certain disorders, e.g., cancer, cystic fibrosis, and mental retardation have been the focus of investigators much more often than others. This imbalance has resulted in frequent generalizations from those well-researched conditions to the less well-studied ones. Due to the fact that each disorder differs from the others along several dimensions, including its etiology, visibility, severity, prognosis, etcetera, the accuracy of these generalizations is questionable. Nevertheless, Pless and Pinkerton (1975) and others advocate that a homogeneous conceptualization of chronic illness based on the chronicity of the illness per se as opposed to any specific aspect of it is most viable. In view of this position and the state of the literature, studies based on samples with physically, mentally, and medically chronically ill children will be reviewed below.

Parents

Emotional functioning. A broad range of emotions and defenses have been reported in parents following the diagnosis of chronic illness in their child including: shock, denial, anxiety, guilt, grief, and helplessness (Binger, Ablin, Feuerstein, Kushner, Zoger & Mikkelsen, 1969; Boone, Baldwin & Levine, 1974; Cotter & Schwartz, 1978; Ehrlich, 1974; Hawke, 1967; Linder, 1970; Meyerowitz & Kaplan, 1967; Raimbault, 1973; Weil, 1968). The defense of intellectualization (Weiner, 1970) and

intensive searching for as much information about the illness as possible, coupled with shopping around for medical opinions (Eiser, 1979) have also been documented.

Though little evidence exists to suggest that mothers and fathers react differently to diagnosis of illness in their child, Knapp and Hansen (1973) and Teyber and Littlehales (1981) contend that dissimilarities in intensity or type of feelings and in coping reactions between husband and wife may occur and result in a compounding or exacerbation of feelings.

Following the diagnostic stage, parents are generally confronted with numerous ongoing stressful situations to which they may react in a variety of ways. The daily regimen of outpatient medical care required by certain conditions has been described as a source of both emotional and physical stress for parents (Kagan-Goodheart, 1977; Weil, 1968). Depending on the illness, it may involve transportation to and from regular medical appointments, in-home therapeutic regimens of exercise, blood testing, urine testing, dietary modifications, medications, respiratory massage, etcetera. This can be time-consuming, costly, and physically exhausing. Some treatment regimens are so demanding that curtailment of leisure activities due to a lack of time and energy to engage in such events have been cited (Turk, 1964). Parental feelings of anger at such extra burdens, irritation with the ill child's relentless demands and needs, and the subsequent guilt experienced because of their anger and resentment toward the ill child have been connected to their overindulgence and overprotection of the ill child (Green, 1968; Rhyne, 1970). These latter tendencies have been interpreted as compensatory reactions for their unacceptable feelings of rejection and hostility.

All parents also encounter numerous emotionally charged issues pertinent to the chronicity of the disease. The decision of whether or not to inform the child of the diagnosis is one such issue. This has been observed to be particularly difficult when the diagnosis is life-threatening (Waechter, 1971). The debate amongst professionals with regard to this issue (see Share, 1972, for a review) does not make this decision easier. Two physicians or health professionals involved in the same case may possess opposing opinions, with the result being confusion and a dilmema for the parents.

What to tell the other healthy children in the household and relationships with relatives and friends are frequently expressed sources of conflict, anxiety and guilt for parents of children with long-term illnesses. With regards to the former, Meyerowitz and Kaplan (1967), in their study of responses to stress in families with a child with cystic fibrosis, found that parents experience much anxiety often associated with conjecture about whether to inform the healthy siblings or not. Gordon and Kutner (1965) observed a similar reaction to this issue.

Furthermore, a paradox seems to be imposed on parents by relatives and friends which creates feelings of social isolation and alienation. While denial of the diagnosis and its implications is perceived as being actively encouraged, parents also feel that they are expected to be grief stricken forever. Thus, they are not expected to participate in normal social activities or to be interested in entertainment. This has been particularly commented on by parents in cases where there is a child with a life-threatening illness such as cancer (Friedman, Chodoff, Mason, & Hamburg, 1963) or cystic fibrosis (Meyerowitz & Kaplan, 1967).

Other problems caused by friends and relatives and revealed by

parents to be awkward to handle entail inappropriate emotional responses to the ill child himself/herself and the inability of others to talk about the ill child's diagnosis, treatment, prognosis, etc. (Kelly, 1979).

Several investigations have found a high rate of emotional morbidity and psychiatric symptomatology severe enough to interfere with adequate functioning amongst parents of chronically ill children. Perhaps the clearest finding to emerge from Minde, Hackett, Killou and Silver's (1972) study of 41 sets of parents whose children were mentally retarded or had cerebral palsy or epilepsy was the complexity of problems associated with raising an "abnormal" child. They discovered that most parents found it impossible to deal with the development of their children on a long term basis and lived from day to day. Lawler, Nakielny and Wright (1966) and Bywater (1981) studying parents of children with cystic fibrosis reported pronounced clinical symptoms of depression in a large percentage of mothers in their study and that the rate they observed exceeded that found in the "normal" population. The former group also found an unusual incidence of psychopathology including psychoses in fathers. All of these studies suffered from methodological flaws such as small sample sizes and poor controls. Nevertheless, their findings are consistent with the well designed and rigorous exploration of Gayton, Friedman, Tavormina and Tucker (1977). These investigators administered a psychometrically well established measure to parents of children with cystic fibrosis and compared the results of this group to parents of noncystic children. Over one third of the fathers and slightly fewer mothers of ill children obtained scores in the range of emotional disturbance, with depression and psychopathic deviance standing out most.

Similar, as well as higher rates of disturbance have been found in parents where there was a child in the family who experienced a relapse of illness, e.g., cancer or died (Friedman et al., 1963; Stehbens and Lascari, 1974). Problems sleeping, loss of appetite, and other symptoms of depression were noted.

Marital relationship. In view of the enormous number of stresses created for parents by chronic illness in their child, the accumulation of a sizeable literature on marital disruption in such families is not surprising. Liberthson (1968) states that when something goes wrong in a family it is natural for both parents to become tense and irritable. They being to search for someone to blame and too often each marital partner may blame the other. McCollum and Schwartz (1972) also remark on the vulnerability of the marriage in such families. In addition to Liberthson's observation, they illustrate several potential stress factors including: the difficulty parents may have in empathizing with the feelings of their spouse; exhaustion and apprehension about further pregnancies which may result in suspension of the sexual relationship; the trouble fathers may have in finding a meaningful role in the care of the ill child; and the wife's absorption with the child's needs possibly arousing feelings of abandonment in the husband.

There is a paucity of methodologically sound studies on the incidence of discord, separation, and divorce in families of children with chronic illness. While some authors mention divorce as part of the stress of chronic diseases in children, only a few studies which attempt to concentrate upon ojbective variables, such as the frequency of divorce, are available. Most information pertaining to the marital relationship

of these parents is derived from interview data.

Farber (1959), Hamovitch (1964), Kaplan et al. (1973), Lawler et al. (1966), Linder (1970), Oakley and Patterson (1966), and Stehbens and Lascari (1974) are amongst those who studied the marital relationship of parents of children with several different chronic illnesses in a relatively unsystematic manner. With the exception of the latter two research teams, who did not find evidence in support of widespread marital disruption, the results reported were consistent in their findings of frequent marital disharmony and dissolution. The discrepancy in findings are likely attributable to variations in methodology, e.g., timing of interviews. Both Oakley and Patterson's (1966) and Stehbens and Lascari's (1974) samples were composed of families in which a child had died from six months to three years prior to the onset of the study. In all the other investigations, the ill child was living or had died up to three months before the interview. Thus, it appears that living with a chronically ill child and experiencing his/her death does pose a threat to stability of parents' marital relationship.

The larger prospective and more objective studies support this conclusion. In 191 families with a child who had cancer, for example, divorce rates were not statistically different from state divorce rates but, increased marital disharmony relative to parents of hemophilic children and parents of healthy children was revealed. Furthermore, death of the child was not associated with divorce. The marital stress seemed to be associated with the diagnostic stage and did not increase significantly as a function of time (Lansky et al., 1978). Contradicting this finding somewhat, on the basis of their longitudinal study Tew et al. (1977) found that the divorce rate for families with a surviving child afflicted

with spina bifida was nine times higher than that for the local population and three times higher than that for families experiencing bereavement of their child. It seems likely that the type of illness and its implications account for the disparate findings re divorce rates of Lansky et al. (1978) and Tew et al. (1977). Despite their differences, both studies do, however, indicate that the quality of relationship between parents of a chronically ill child often becomes strained at some point(s) during the illness experience, that death is not the worst period for parents, and that the marital dysfunction may or may not lead to divorce.

Variables that may moderate parental adaptation. Though rigorous study of the variables that may influence the adaptation made by parents of children with chronic illnesses has not occurred to date, discussion of potential intervening factors has been frequent.

a) Ability to master self-accusatory and guilt feelings.

The ability to master feelings of self-blame over having transmitted or in some way "caused" the child's affliction has been suggested on the basis of clinical impression, as a crucial factor in determining parents' acceptance of their child's medical condition and long term successful adaptation to it (Mattson, 1972). Data regarding the number of parents who actually accomplish this feat is not documented, however.

b) Past experience with crises, death, and illness.

Both Adams (1979), Anthony (1973), and Friedman (1976) in offering their clinical experiences with parents of children diagnosed with cancer, assert that parents respond to the stress of illness in their child in ways which have been learned through previous encounters with crises, illness and death. It is suggested that couples who have accumulated

considerable experience in dealing with crises may have developed sufficient strength to help them cope with this severely stressful problem. Those who lack experience in this respect, on the other hand, are not expected to deal effectively with the stress of their child's illness.

c) Age of the child.

Sources tend to agree that illness in an older child is more stressful to parents than illness in a younger child. In his attempt to systematically study families of retarded children, Farber (1959) found that there was little differences in marital integration between parents with a young child (less than nine years of age) at home and parents with a young child in an institution. The degree of marital integration of parents with an older child at home (greater than nine years of age), however, was lower than that of parents with an older child in an institution. Similarly, Hamovitch (1964) contended that parental adaptation to their child's illness was most uneventful when the child was in the age range of five to nine years. Problems adjusting to the illness were most difficult when the child was ten years or older.

Although both of the above studies suffer from flaws in research design (e.g., absence of control groups), their findings are supported by Robertson's (1978) clinical report on families of adolescents who are ill. He suggests that parents may have more difficulty coping with the stress of an older child's illness because they have to deal with both their lost hopes and dreams and with the increasing independence, poor communication, defiant acts and alienating behavior of the maturing child.

d) Education, socioeconomic status and religion.

Murstein (1960) refers to the moderating role of educational level, occupation, and intellectual level on the emotional adjustment of parents of children with leukemia and other malignant diseases. No other mention of these variables occurs in the literature.

With regard to the influence of religious beliefs, Heffron, Bommelaere and Masters (1973) report that for parents who attended their group support meetings, religion was often a source of strength. It provided a framework of belief through the provision of a suitable explanation of the purpose of life, illness, and death. However, the authors also note that religious conviction was not a source of comfort for all the parents of children with long-term conditions participating in their group meetings.

e) Gender of the child.

With the exception of those investigators with an interest in factors moderating parental adaptation in families with a retarded child, the influence of the ill child's gender has received no attention. However, the importance of a retarded child's sex in parental ability to cope is clearly reflected in these studies, despite the unsophisticated methodology. Farber (1959) found that parents of retarded boys were helped in their marital integration by institutionalizing their child. This finding did not hold for parents of retarded girls. Similarly, Levine (1965-66) concludes that male retarded children are more difficult for parents to cope with on an emotional level than female retarded children and that sex of the child should be considered in any analysis of the family constellation and in counselling efforts.

f) Nature of illness.

Although numerous anecdotal accounts and clinical observations

suggest that adjustment to life-threatening illness in their child is more difficult for parents than to nonlife-threatening illness (Davis, 1975; Debuskey, 1970; Friedman, 1968; Knapp & Hansen, 1973; Paykel, Note 3; Vernick, 1973), only one study has addressed itself to this variable. Lansky and colleagues (1978) in their research on parental discord and divorce in parents of children with cancer (a life-threatening disease), disclosed more marital stress in this group than a comparison group of couples who had hemophilic children (a nonlife-threatening illness).

Several variables have been proposed as correlates of parental adaptation to illness in their child. Rigorous examination of the relationship between any of these factors and degree of adjustment is lacking,as is study of the influences of these variables on a wide range of chronic illnesses. The impact of various dimensions upon which chronic diseases differ (i.e., their potential fatality or nonfatality; hereditary vs nonhereditary etiology; stability) on parental adjustment has not been the subject of systematic inquiry either. As a consequence, binding statements regarding the role played by these potential intervening variables cannot be made.

Summary and critique. A bleak picture of the emotional adjustment of parents with chronically ill children is painted in the literature. Although writers who adopt a crisis perspective in analyzing the situation suggest the possibility of both a positive and a negative outcome for families as well as individuals within them (Caplan, 1974; Golan, 1978), the majority of the literature indicates that parents frequently experience an intensely adverse emotional reaction in response to chronic

illness in their child as well as increased marital tension.

The role of a number of variables in either allaying or aggravating the adaptation achieved by parents of chronically ill children has received minimal attention from investigators, although a few reports are available. Among the variables that have been suggested as moderating the psychosocial adjustment of parents are the following: age and sex of the ill child; parental ability to master feelings of self-blame and guilt over having transmitted or in some way "caused" the disease; past experience with crises, illness, and death; educational level, socioeconomic status and religious beliefs; and nature of the illness.

Unfortunately, most reports on the impact of chronic illness on parents' adjustment and on the role played by intervening variables suffer from one or more methodological weaknesses. As has been pointed out throughout this review, many studies lack adequate controls. In fact, the majority of investigators did not include comparison groups of any sort. Thus, for example, it is possible that the emotional reactions and marital instability described above are not due to the chronicity factor of the illnesses studied but to some other variable(s). Further, in several investigations, participants were not matched on potentially important factors. The etiology of the illness (whether it is a hereditable disease or not) may influence adaptation (Reinhart, 1976), but has not been controlled or systematically studied as an intervening variable. Likewise, additional scrutiny of the life-threatening aspect of a disorder and whether this dimension creates a more emotionally hazardous impact on parents is necessary. Furthermore, in diseases with a natural history of exacerbations and remissions, rigorous examinations

of differential effects caused by the stage of the disease have not been undertaken. In still other cases, conclusions are based solely on retrospectively attained interview data and interviewers' subjective opinions and ratings. Objective, standardized measures with good reliability and validity have been utilized only rarely. More questionable results derive from reports based on professionals' personal experiences with parents of chronically ill children. Such case studies and anecdotal information constitute a large segment of the literature.

The virtual absence of elegant experimental designs and sophisticated methodology that characterize this literature is obvious. Nevertheless, it does seem to converge on revealing a high risk for disruption of the psychological homeostasis of parents. Emanating from a recognition of these potential adverse effects, several hospitals and clinics now offer support groups to parents of children with a variety of chronic illnesses (Heffron, et al., 1973; Linder, 1970).

The Chronically Ill Child

Emotional functioning. Several reports describe the emotional reactions of children with chronic medical conditions and suggest that this population is more likely to experience psychosocial difficulties than their healthy peers. Many investigators also contend that these secondary non-physical consequences of illness may prove to be more disabling in the long run than the direct effects of the disorder.

Mattson (1979) points to the multitude of emotionally stressful situations, often of a recurring nature, which all children with chronic illnesses encounter and which pose psychological threats. He

includes having to deal with hospital admissions, routine medical visits on a frequent basis, various treatment procedures which may be painful, uncomfortable, and/or invasive of privacy, in-home therapeutic regimens, changes in the emotional climate of the family, and interference with schooling and leisure activities. Numerous other investigators concur that the chronically ill child faces difficult situations which are different from those confronted by healthy children and are superimposed on the normal crises of development. They are thus placed at risk for psychosocial maladjustment (e.g., Boone, Baldwin & Levine, 1974; Ehrlich, 1974; Erikson, 1959).

Several authors have reported considerable psychological upset in the child with cystic fibrosis (Cytryn, Moore & Robinson, 1972; Lawler, et al., 1966; McCollum & Gibson, 1970; Spock & Stedman, 1967), juvenile diabetes (Ehrlich, 1974; Swift, Seidman & Stein, 1967; Zeidel, 1973), renal disorders (Korsch, 1976), spina bifida (Dorner, 1976), cancer (O'Malley, Koocher, Foster, Slavin, 1979; Spinetta & Maloney, 1975; Spinetta, Rigler & Karon 1973), and juvenile rheumatoid arthritis (McAnarney, Pless, Satterwhite, and Friedman, 1974). Heightened anxiety levels, decreased self concept, a greater incidence of psychiatric disturbance, distortions in body image, social inadequacies, behavioral problems, and school difficulties are among the negative effects discussed by these investigators.

In contrast to the above findings, a number of studies exist which report the absence of unfavorable effects on the emotional adaptation of chronically ill children. Bywater (1981) and Gayton and colleagues (1977) for example, both state that the children with cystic fibrosis

that they studied were generally within normal limits of personality functioning. Likewise, Klein (1975) notes that only a small group of the children with chronic kidney disease that she interviewed had significant problems in adjustment. Most patients were found to be coping surprisingly well. Similar findings emerged from the work of Korsch et al. (1973) and Fergusson (1976) who studied kidney transplant and cancer patients respectively. Results in the same direction were also obtained by Tavormina, Kastner, Slater and Walls (1976) as well as by Kellerman, Zeltzer, Ellenberg, Dash, and Rigler (1980) and Zeltzer, Kellerman, Ellenberg, Dash, and Rigler (1980) in their samples of children with various chronic diseases.

How does one make sense of these equivocal findings? For the most part, it seems as if the discordance can be attributed to the diversity in methodological rigor of the studies cited. Differences in the severity of illness in the children studied, length of time since diagnosis, presence of control groups, and size and representativeness of samples on which results are based are evident amongst these investigations. Moreover, many reports relied exclusively on clinical impressions or interviews, while others employed more psychometrically established instruments but of variable quality. The studies utilizing more formal measuring instruments generally seem to be the ones documenting less maladjustment, while those based on subjective evaluations report more maladjustment. The use of different philosophical models, i.e., normalcy as opposed to deviancy when studying this population, also seems responsible for the ambiguous findings.

The three most methodologically sophisticated studies of childhood chronic illness (described earlier) provide some clarification of the

confusion existent in the literature. By virtue of the longitudinal nature of the National Survey of Child Health and Development, the utilization of well-matched control groups in both the Isle of Wight study and the Rochester Child Health Survey, as well as the sophisticated sampling methods employed in all three surveys, the researchers ensured that to the extent that higher rates of secondary handicaps were found in groups of chronically ill children differences could not be attributed to other variables (e.g., social or demographic). That is, because of the elegant research design of these studies, excess rates of psychosocial problems could be attributed to the chronicity of the disorders.

The results of the Rochester Child Health Survey revealed that the frequency of psychological maladjustment as assessed by three sources (parent, teacher, and patient ratings), was 10-15% greater among the chronically ill than among healthy controls. In addition, this investigation indicated that the effects of poor health are cumulative over time. Both this survey and the National Survey attested to higher rates of behavioral and psychiatric maladjustment among chronically ill children of primary and secondary school age that took the form of increased truancy, social isolation, and attitudinal problems. Twenty-five per cent of the ill children in the National Survey had two or more abnormal behavioral symptoms, compared with only 17% in the healthy population. The Isle of Wight study exhibited that the rate of psychiatric disorders among the chronically ill youngsters was 17% compared with only 7% in the healthy population. There was the same proportion of chronically sick children with neurotic and anti-social behavior patterns as in the

general population.

In terms of educational achievement, a significantly higher proportion of children with chronic diseases,as compared to a control group, was retarded by 28 months or more below their expected level of reading achievement, after age and IQ had been taken into account (Isle of Wight study.). Lags in educational achievement were also indicated by the National Survey. The average aggregate scores on tests of achievement for chronically ill children were significantly below those of healthy children.

Pless and Roghmann (1971) conclude that the data from these three independent investigations show that a high proportion of the social and psychological disturbances must be attributed to the chronicity of the disorders. Furthermore, they declare that of the 10-15% of children who experience a chronic illness, 30% may be expected to be handicapped by secondary social and psychological maladjustment. This conclusion seems merited in view of the elegant methodological techniques utilized in these three surveys,but has been questioned by some authors who suggest that the association between disease and poor adaptation can be interpreted as reflecting causality in the reverse direction. That is, these investigators claim that the emotional dysfunction is the cause of the physical condition. Pless (Note 4) addresses this argument and asserts that, in addition to common sense, there is some data to refute this psychosomatic hypothesis for most medical conditions under consideration.

Taking the results of all the studies conducted to date into account, it seems clear that children afflicted with chronic illness are at increased risk for the development of secondary psychosocial difficulties. However, it is also apparent that the extent of the increased risk is much smaller than previously predicted. Although several studies may

lead one to believe that many, if not all, chronically ill youngsters would have some significant psychosocial concomitants, this does not seem to be the case. Pless (Note 4) in this regard raises the issue of instrumentation and alleges that it may be that many children do experience psychosocial problems but that the measures that have been employed have failed to detect them.

Given the limitations of the measuring tools used to date, the proportion of increased risk seems to be in the range of 2-2½ times according to Pless. Thus, as many as 70 or perhaps 80% of children with chronic conditions seem to be free of significant emotional difficulties. The question that arises from this finding is what factors serve to distinguish those children who are most likely to experience such problems from those that are not?

Variables that moderate the occurrence of maladjustment in chronically ill children.

a) Parental coping.

Although for purposes of this review the emotional reactions of the chronically ill child have been considered separately from those of the parents, the two appear to be intimately connected. Tropauer, Franze, and Dilgard (1970) have shown that the coping responses of the child with a chronic condition reflect the style of his/her parents. Likewise, according to Mattson (1972), children with prolonged poor adjustment to their disease fall into three groups. Each group is characterized by a specific parental response. Those with passive-dependent personalities are observed to be commonly raised by constantly fearful and overprotective mothers and to demonstrate fearfulness, inactivity, lack of friends and outside interests, and prolonged dependency on their families, especially

their mothers. The second group consists of overly independent children whose reality sense seems impaired and who are often reared by over-solicitous and guilt-ridden mothers. They may engage in prohibited or risk-taking activities. Children in the third category are described as possessing hostile attitudes toward the environment related to early parental attitudes of embarrassment and shame of having a defective child. They are observed by Mattson (1972) to often impress as shy and lonely patients.

In their study of adaptation of families with a hemophilic child, Mattson and Gross (1965) found further evidence for the influence of parental coping styles and attitudes. In each of the 22 families they studied, maternal level of adjustment was a correlate of successful or unsuccessful adaptation on the part of the ill child.

The importance of a positive and supportive relationship between the ill child and mother was also identified by Klein (1975) in her study of chronic renal disease, and by de Traubenberg (1970) in his work with pediatric cardiology patients, and by Steinhausen and Schindler (1981) in their study of families with a child who had Cystic Fibrosis.

b) Level of family functioning.

Cytryn et al. (1973) and Zeidel (1973) both note that the children who were best adjusted in their studies came from warm, stable families and that family variables were predictive of a good or poor prognosis for positive adjustment.

Through the use of an index based on responses to questions about family relationships, marital satisfaction and happiness (Family Functioning Index - Pless & Satterwhite, 1973), the Rochester Child Health Study (Pless et al., 1972) assessed the significance of family functioning. The authors report that in the prediction of each of their psychological

measures, family functioning counted more heavily than such aspects of family structure as socioeconomic status, parents' health, education and age. Furthermore, they found that children with chronic disorders could be classified into high and low risk groups for the development of secondary psychological consequences on the basis of their scores on the Family Functioning Index. Children from families with lower scores on this index constituted more of a risk than those from families with higher scores.

Although replication of the results of this investigation are needed, its sophisticated methodology (described earlier) strengthens the implications for the very important role played by family functioning in influencing children's adjustment to their chronic illness.

c) Age.

Several investigators allocate a rather large moderating role to age of the child on her/his adaptation to illness and discuss adjustment according to a developmental framework (Mattson, 1979; Morrissey, 1963; Plank, 1962; Waechter, 1971). The work of Bibace and Walsh (1979) on developmental stages in children's conception of illness supports these allegations. On the basis of a large scale study, they classified children's responses to questions about the nature and cause of illness in terms of Piaget's broad states of cognitive development and were able to differentiate two subcategories for each stage.

Adolescents are commonly viewed as experiencing the most difficulty coping with their illness (e.g., Robertson, 1978) since illness interferes with age appropriate strivings for independence. Nevertheless, according to Pless (Note 4), if age is important it only operates in conjunction with certain characteristics of the disease. The most current reports of Kellerman et al. (1980) and Zeltzer et al. (1980) lend credence to this conclusion.

d) Gender.

While the literature indicates a preponderance of boys over girls with chronic disorders (Pless & Douglas, 1971), it does not reveal any differences between boys and girls in psychosocial adaptation. Here again Pless (Note 4) states that it is likely that this factor does not operate alone. Rather, features of the illness need to be taken into consideration. For example, there are suggestions in some studies that females are more maladjusted when physical appearance is affected by an illness (Zeltzer et al., 1980).

e) Premorbid personality traits.

Pless comments that premorbid personality traits and temperamental traits are almost certainly of importance but, due to the fact that so few studies are longitudinal, there is little direct evident to support this contention.

f) Characteristics of the illness.

In the earlyliterature there were numerous suggestions that certain diseases were accompanied by specific personality disorders. This has not been validated by controlled research however (Pilling, 1973).

Very few studies have tried to determine the comparative significance of various types of disability (e.g., medical, sensory, cosmetic) and the data that is available is equivocal (Pless et al., 1972; Pless, Note 4).

Similarly, there exists much ambiguity regarding the role of severity of disease. Though some researchers present evidence of maladjustment increasing in proportion to severity (Steinhauser & Schindler, 1981), others offer data which supports the "marginality" concept, i.e., the less severe the disorder the more prone the individual to struggle between viewing himself/herself as normal versus deviant (Bruhn, Hampton, & Chandler, 1970; McAnarney, Pless, Satterwhite & Friedman, 1974).

Among the other disease-related variables that have been examined are the degree of life threat imposed, age of onset, duration, and nature of therapy. There is some suggestion that the more life threatening the illness the greater the likelihood of psychosocial difficulties (Davis, 1975; Spinetta & Maloney, 1975; Spinetta et al., 1973; Waechter, 1971). However, inconclusiveness regarding the intervening role of these other features prevails.

It thus seems evident that a number of the variables discussed above may influence the type of adjustment achieved by chronically ill children. These variables, however, require rigorous experimental study if one is to attain a clearer comprehension of the way they influence the child-patient's adaptation.

Summary and critique. A rather large number of studies now exist which provide evidence that children with chronic medical illnesses are at increased risk for psychosocial maladjustment. Nevertheless, the evidence is not as conclusive as desired due to methodological shortcomings. A lack of normal controls, sampling biases, reliance on subjective clinical impressions and interview data especially characterized the early studies. Later investigations adopted more rigorous controls and objective measures of functioning but the quality of measuring instruments used was often suspect. Furthermore, for the most part, the studies that have been reported are essentially cross-sectional and most have assumed a pathology orientation.

What is perhaps most interesting and surprising in reviewing the

results of these studies is the fact that, acknowledging the limitations of the instrumentation employed to date, the extent of the increased risk is in the range of 2 - 2½ times and is much smaller than many investigators expected. This data poses the challenge of identifying those factors that distinguish children who are most prone to experience psychosocial difficulties from those who may remain free of problems.

Several variables that may be associated with the occurrence of maladjustment have been discussed and/or studied. However, firm conclusions about their role as moderators of adjustment is not possible presently. Further research of a rigorous nature is required in order to elucidate their importance.

Siblings of Chronically Ill Children

In contrast to the extensive body of literature demonstrating awareness of the complex reactions and effects of childhood chronic illness on parents as well as the child patient, a relatively small number of studies are devoted to the impact of this experience on the healthy children in such families. This is not to say, however, that investigators do not realize that the siblings of children with long term illnesses may also be affected by this experience. Anecdotal comments abound with respect to this subunit of the family, and retrospective subjective observations permeate the literature. The primary focus of comments and/or studies conducted has been on the disturbed reactions of siblings to the death of their brother or sister. Few systematic studies direct attention to sibling adjustment during the disease process. Interestingly, several investigators label their research as an examination of the impact of a chronic illness on the "family". None of these studies,

however, pays more than lip service to sibling adaptation. Some do not even mention siblings. Perhaps due to an entrenchment in the medical model which suggests focus on the "patient" and his/her parents (especially the mother), we seem to have barely progressed beyond the time when lengthy, intensive, psychiatric case studies could note in a passing sentence that "the patient's sibling died when he/she was four" and omit any further references to the event's meaning to the patient.

Why should siblings of ill children receive more attention from researchers? Studies examining sibling reactions to death of their brother or sister, research on the stressfulness of life events for children, and preliminary investigations into the impact of the disease process on siblings all speak to the necessity of including sibling reactions in conceptualizing and comprehending the full effects of a long-term childhood disorder. Furthermore, family systems theory and studies documenting disequilibrium in family functioning where there is a child member with a chronic illness augment this need. Each of these arguments will be examined below.

Sibling reactions to death of their brother or sister. Though most studies on sibling reactions to death of their brother/sister are retrospective and uncontrolled, a number of investigators have attempted to assess the comparative incidence of early sibling deaths and the process of bereavement among a variety of clinical groups (Blum & Rosenzweig, 1944; Pollock, 1962). The results suggest that the process of bereavement in this context may show striking differences from other contexts of loss and bereavement (e.g., loss of a parent or spouse, or parents' loss of a child). Other reports center on a debate regarding the child's capacity for mourning the loss of a sibling (Furman, 1964;

1973; Nagera, 1970; Wolfenstein, 1966) and make anecdotal references to maladaptive reactions on the part of the surviving sibling(s).

Responding to the relatively neglected territory of children's reactions to death, Cain, Fast & Erickson (1964) undertook such an investigation. They examined case material derived from closed files of child psychiatric patients whose major symptoms were judged (by the authors) to be substantially related to the death of a sibling. This method of data collection leaves much to be desired methodologically as do the following aspects of their research design. The material they examined ranged from outpatient psychiatric evaluations to years of intensive inpatient treatment, with cases seen in various settings. Further, the sibling deaths among the cases studied ranged widely from chronic or sudden illnesses through car accidents, drownings, burnings, accidental shootings, severe beatings and murder. The remaining siblings' actual involvement in or "responsibility" for the death similarly was of a wide range. Nevertheless, their findings are interesting, and if viewed cautiously, suggest potential disturbances in affect, cognition, belief systems, superego functioning and object relationships.

The most dramatic observation made on the basis of this clinical data is that a child's personality is sometimes altered for life by the death of a sibling. Other disturbed reactions noted by these researchers include (1) guilt manifested by depressive withdrawal, accident-prone behavior, punishment-seeking and many forms of acting out; (2) deterioration in school functioning; (3) distorted concepts of illness and death and the relationship between illness and death, particularly in those children whose brother or sister died due to illness; (4) heightened

fears of doctors and hospitals, especially in those children who had lost a sibling to illness; and (5) derangement in cognitive functioning in a manner distinctly different from poor school performance, i.e., encapsulated ignorance and distortions in previously well-known concepts.

Binger (1973) concurs with several of Cain et al's (1964) observations. Commenting on reactions of children to the death of a sibling from a life-threatening illness, he mentions not only immediate psychological symptoms associated with grief, but also enduring symptoms and distortions in character structure such as preoccupation with inner fantasies around death.

Less severe disturbances have been reported by Stehbens and Lascari (1974). Only transient behavioral problems (dysphoria, enuresis, abdominal pain, restless sleep, declining school performance) were related by the parents of children who had lost a brother or sister due to leukemia. Seventy per cent of the siblings were judged to be back to normal within one week of the child's death.

Discrepancies among findings may be due to differences in sample size, in the medical and psychosocial care provided, or in definitions of disturbances. A more likely explanation of these very opposing findings, however, is the time interval between the child's death and the collection of data. As indicated in a preceding section of this review, Stehbens and and Lascari (1974) followed families who had lost a child 6 months to three years prior to their investigation. Hence, parental comments about the adaptation of the siblings may have been subject to errors of memory and even denial. It is also possible that the disparate results stem from the very different samples surveyed by these authors and by Cain et al. (1964). While Stehbens and Lascari (1974) based their findings on 20

volunteer families who had a child treated at the university hospital they were affiliated with, Cain and coworkers (1964) looked at a very select sample of children who had experienced death of a siblings, i.e., psychiatric patients. It must also be noted that psychological testing was not utilized in any of these studies and opinions are based primarily on parents' perceptions or researchers' interpretations of case files. The data presented is thus not quantifiable.

Due to the methodological weaknesses described above, all of the findings delineated should be viewed as tentative and in need of validation by rigorously designed and executed studies which are not only oriented to identifying pathological or deviant reactions but also attempt to identify normal functioning. Nevertheless, the available results are consistent in their suggestion of adverse consequences stemming from death of a sibling. They also raise the question of the onset of disturbed functioning in those cases where a child died as a result of illness. It may be that the maladjustment observed was actually present during the course of the disease but was not revealed because of the retrospective time frame of the investigations reported.

Stressfulness of life events for children. Extrapolating from the work of Holmes and Rahe (1967), Coddington (1972 a, b) surveyed over 3500 healthy children and assessed the significance of social-psychological events that commonly occur in children's lives. Based on the premise that any event that requires a readjustment on the part of an individual constitutes a stressor or psychological trauma and that an accumulation of changes within a given period may generate symptoms, he established the relative value of different events by assigning a weight in Life Change Units (LCU) to them. The rank order of events was also attained

by having teachers, pediatricians, and mental health workers rate the importance of these life events. Remarkable agreement amongst the raters was noted. No large significant differences appeared in the rank order assigned to the items in any age group by group or subgroup of respondents. In all four age groups he studied (preschool, elementary, junior high, and senior high), sibling illness and sibling death ranked among the most stressful of the approximately 42 life events on the survey. In light of Coddington's contention that an accumulation of LCUs within a given period may generate symptoms, the siblings of chronically ill youngsters constitute a high risk group.

Preliminary reports suggesting an adverse impact of chronic illness on siblings. Several reports coincide in their conclusion that the siblings of chronically ill children may actually bear the greatest burden of stress and receive less support and understanding from their parents (Crain, Sussman & Weil, 1966; Pless, 1976; Poznanski, 1973). However, to reemphasize an earlier point, there is a scarcity of literature on the subject of siblings of chronically sick youngsters and, of the relatively few articles available, most are anecdotal accounts or inadequately controlled studies. Hence, the conclusion reached by these researchers is questionable and must be viewed with caution until further systematic investigations are conducted. The handful of more systematic studies available, nevertheless, do support this observation. Findings accruing from both methodologically respectable and methodologically weak studies will be reviewed below, due to the small amount of relevant literature on siblings.

Lavigne and Ryan (1979) examined the behavioral adjustment of a large group of siblings of medically ill children from three different

clinic populations (plastic surgery, hematology, and cardiac disorders) as well as a small control group of siblings of healthy children. Using the Louisville Behavior Checklist, an objective measure of personality functioning, they found that the siblings of the patient groups were more likely to show symptoms of irritability and social withdrawal. As pointed out by the authors, the four groups differed on three relevant variables which can be related to the symptoms measured by the behavior checklist they employed. Thus, differences between groups could be due to these variables rather than the effects of the illness per se and this study loses some of its meaningfulness.

The only other investigation pertaining to siblings of medically ill children which used objective measures of personality and a control group found evidence in support of maladjustment in this population. Tew and Laurence (1973) documented a significant difference between the siblings of patients and a matched group of siblings of healthy children on the Bristol Social Adjustment Guide. The siblings of children with spina bifida were nearly four times more likely to show evidence of maladjustment in school than the siblings of control children.

The results of two other methodologically sound studies concur with the work of Lavigne and Ryan (1979) and Tew and Laurence. However, they focused on a somewhat different population of siblings, i.e. siblings of mentally retarded children. Gath (1973) studied 143 siblings of children with Down's Syndrome living at home and compared their behavioral rating (by parents and teachers) with those of 143 matched control siblings of normal children. She found that 20 per cent of the former group were rated deviant by either parents or teachers versus 10 per cent of the control group. This difference is significant at the $p < .05$ and

$p < .001$ level respectively, when girls alone are considered. No significant differences between the boys in the two groups were observed. In fact, nearly the entire difference between the two groups of siblings could be accounted for by the increase in anti-social behavior in female siblings of children with Down's Syndrome. In descending order of frequency, the symptoms exhibited by these girls were difficulty with peer relationships, restlessness, disobedience, misery and temper tantrums.

Tritt (Note 1) investigated the emotional and behavioral adjustment of children with institutionalized retarded siblings as compared to that of a matched group of children with non-retarded siblings. As predicted, children with retarded siblings indicated significantly lower overall emotional adjustment, significantly depressed affect in the family situation, and significantly less happiness on a self-report measure of self-concept tapping four areas (peer, academic, family, general). The incidence of anti-social behavior was also found to be significantly elevated in the group of children with retarded siblings, according to parental reports on the Behavioral Problem Checklist. No sex differences were observed.

A number of other recent investigations have made the siblings of chronically ill children their subject, but failed to employ control groups, adequate sample sizes and/or objective, well established measurements of adjustment. Some of their findings lend validity to those described above, whereas others contradict the suggestion of maladjustment in siblings of chronically ill children. The result is confusion and uncertainty about the effects of the chronic illness experience on

siblings.

Gayton et al (1977) examined a very small group of siblings of children with cystic fibrosis and had them complete a measure of self-esteem and two projective tests. Though they did not have a control group, they conclude that evidence for a negative psychological impact of chronic illness on sibling development is lacking. They do, however, acknowledge that it is possible that the negative psychological consequences associated with cystic fibrosis were not manifested on the measures they used.

Breslaw, Weitzman, and Messenger (1981) found siblings of children with various disabling diseases (cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps) to score higher than controls on measures of mentation problems, fighting, and delinquency, although overall impairment was not significantly different.

Though based entirely on interview data with a small group, Harder and Bowditch (1982) claim that many of the siblings of children with cystic fibrosis benefited from the illness experience. They offered evidence of personal growth and increased family cohesion.

In contrast to the positive effects described above, Cairns, Clark, Smith and Lansky (1979) gave school-aged cancer patients and their siblings one or more of three psychological tests (Piers Harris Self Concept Scale, Bene-Anthony Family Relations Test, Thematic Apperception Test) in order to explore the impact of cancer. Although the representativeness of this sample is unknown, and the measurement tools utilized have suspect validity and reliability, siblings showed even more distress than the patients in the areas of perceived social isolation, perceptions of their parents as overprotective and indulgent of the sick child, fear

of confronting family members with negative feelings, and concern with failure.

A study by Carandang, Folkins, Hines and Steward (1979) presents preliminary data suggesting that sibling illness may interfere with developmentally appropriate levels of illness conceptualization. The 36 children who had siblings chronically ill with diabetes, had significantly lower illness conceptualization scores than a matched control group of 36 children with healthy siblings.

Farber (1959, 1960) interviewed 240 families with severely mentally retarded children. He reports two significant effects of the retarded child on siblings: (1) siblings younger than the retarded child assumed a superordinate role, and (2) a female sibling was often encouraged to become a surrogate mother to the retarded child. Those girls assigned parental roles showed higher levels of tension, anxiety, and conflict with mother on psychological testing. Those girls not assigned a custodial role exhibited no significant differences from male siblings. No comparisons with a matched control group of children not having retarded brothers or sisters were attempted and data on the reliability and validity of the psychological tests employed are absent.

Taylor (1980) talked with both the siblings and parents of children with congenital heart disease, asthma, and cystic fibrosis in an attempt to determine sibling adjustment. Only four of the 25 families expressed feelings that the illness had had no effect at all on the well siblings. The remaining sets of parents could identify specific behaviors emerging in their well children that they felt were negative or not helpful within the family constellation. Jealousy, increased competition and fighting among siblings, anger, hostility, social withdrawal, attention seeking

actions, and a decline in school performance were behaviors frequently reported by the parents. Furthermore, two-thirds of the siblings own statements revealed that they experienced feelings of isolation, deprivation, inferiority, or inadequate knowledge about some aspect of the ill child's condition. Aspects of the ill children's lives that had the greatest effect on the well siblings were the parent-ill child relationship, the medical care and treatment, and play and socialization.

Many of these same reactions have been anecdotally referred to in siblings of children with other chronic diseases. Hawke (1967), Mattson and Gross (1965), Turk (1964), and Levin (1970) have all commented on one or more of the symptoms delineated above with regards to siblings of children with cerebral palsy, hemophilia, cystic fibrosis, and nephrotic disease, respectively.

In summary, though, there are a few studies which report findings suggestive of a positive adaptation or the absence of negative consequences on the part of siblings of chronically ill children, most of the data seems to converge on indicating an increased incidence of maladjustment in this population. Nevertheless, the majority of investigations suffer from serious methodological shortcomings and none have assumed a longitudinal perspective. Moreover, with the exception of a couple of studies, siblings have not been directly questioned about their experience. All of these problems prohibit definitive conclusions, generalizability of findings, and the clinical application of results.

Family systems theory. A system is defined as a structure composed of a set of elements and a set of rules that specify the relationship among the elements (Forrester, 1968; Gray & Rizzo, 1969). Over the past fifteen years, the literature about families has been organized increasingly

around this concept of the family as a system to emphasize the relationships between all family members (Bowen, 1966; Framo, 1970; Haley, 1964; Minuchin, 1974; Satir, 1971). According to this conceptualization of the family unit, an acute or chronic illness in any member of the family inevitably affects the other members of the system in some way (Beavers, 1977; French, 1977).

Family as well as individual reactions in coping with the stress of illness are emphasized by Kaplan and coworkers (1973) since they view the family as having a unique responsibility for mediating the reactions of its members. In line with systems theory, these authors contend that when individuals belong to families they do not resolve their own problems of stress independently, nor are they immune to the effects of stress that may be concentrated in another member of the family.

The developmental-transactional model of the family presented by Anthony and Benedek (1970) shares much in common with general systems theory. It sees the family, like the individual, as developing its own special identity that is a composite of the system of identifications operating within it. As the family identity consolidates, a "family likeness" begins to consolidate and members display the same basic coping skills, personality characteristics, defense mechanisms and psychopathology (Anthony, 1973). It is also alleged that depression and anxiety are particularly contagious affects within the family and that a dominant parent can often set the emotional tone of the entire family unit.

Both systems theory and the developmental-transactional model of

the family appear to have implications for sibling reactions in families where there is a child member with a chronic illness. Firstly, as specified by the former, illness in any family member always affects all other members of the family unit. Thus, despite the paucity of systematic literature documenting sibling reactions, siblings cannot escape from the family state of affairs by virtue of the interdependence of family members. Secondly, siblings may be expected to respond to illness in a brother or sister because of the well-evidenced impact this situation has on their parents. Both systems theory and the developmental-transactional model posit a relationship between parental response styles and the coping modes of other family members. Advocates of the former claim that this is because disruption of the psychological homeostasis of a parent inevitably forces upon other family members an alteration in their psychological adjustments (e.g., Watson, 1963). Evidence in support of a relationship between parental coping and the adaptation made by the sick child (reviewed earlier) upholds this contention.

Anderson (1981), Bruhn (1977), Binger and associates (1969) and Kaplan and colleagues (1973) all report on the potential adverse impact of childhood chronic illness on the family unit. All of the participants in Anderson's study related some form of lifestyle adjustment which was the direct result of a child's sickness, while high rates of family breakdown in association with diabetes mellitus, hemophilia and epilepsy are discussed by Bruhn (1977). The other investigators revealed a high rate (50 - 80%) of family failure to cope adequately with the consequences of childhood cancer. Problems with both the well children in these families and with the parents were noted. Marital difficulties, pre-

occupation with the health of the well children, and drinking problems were some of the difficulties remarked upon in the parents, while problems at school and somatic complaints were observed in the healthy children in the family. These investigations also intimate a correspondence between parental coping and the impact of illness on other family members.

In sum, it appears that the connective fascia of the entire family becomes stressed when a member of the family is afflicted with a chronic disorder (Cohen & Wellisch, 1978). The consequences for well siblings, therefore, cannot be ignored.

What aspects of family functioning may be affected by the presence of a chronically ill child member and contribute to the high rate of breakdown in these families?

According to Isaacs and McElroy (1980) continuous care of the chronically ill child necessitates a shift in priorities, creating new and frequent strains on all family members. These authors point out that the mother's committment to the child's care may make it impossible for her to maintain her former degree of attention to her husband's emotional and practical needs. He may be resentful of this situation, with reciprocal hostility depriving both of the mutual support they need. Effects on the marital relationship of parents were reviewed previously and much evidence exists to support the view that chronic illness frequently results in increased stress in this sphere, but does not necessarily lead to separation or divorce. Nevertheless, problems in the marital relationship weaken family relationships (Kaplan et al., 1973), and in this respect have implications for the ill child and her/his siblings.

Readjustments in the parent-ill child relationship have been documented in families where there is a child suffering from a chronic

disorder. In discussing the management of such a child, Green (1968) makes two comments which are pertinent to family functioning and which are reiterated over and over again in the psychosocial literature on chronic illness in childhood. First is the observation that child rearing practices are frequently distorted in these families and second is his reference to the feelings of marked inadequacy as caretakers that parents of such children often report.

These two observations seem intimately connected. That parents who question their adequacy as caretakers should modify their child-rearing practices is not surprising. In addition, that they should amend them so that they experience more positive feelings or reinforcement and less negative feelings seems logical. However, it is apparent in reviewing the literature that some of these alterations are unhealthy for all family members--the ill child, the parents, and the well siblings in the family (Poznanski, 1969). Though little empirical data exists to document this notion, several investigators have illustrated the unhealthy patterns of child care which are often present in parents of children with long-term illnesses. Some of these distorted practices will be described below.

Discipline presents a major problem for parents of children with chronic disorders. According to Freud (1952) there are few parents who do not change their own attitude to the ill child. Brewer (1968) for example, has commented on this issue in parents of children with juvenile rheumatoid arthritis and Friedman and associates (1963) have noted this difficulty in parents of children with cancer. One explanation for this alteration is posited by Poznanski (1973). She alleges that discipline usually entails a measure of anger, and to direct anger and

aggression toward a sick child evokes tremendous feelings of guilt. The result is that parents lessen their disciplinary demands or expectations and are more permissive with their sick child and, in this way, are not confronted with their anger.

Others have also argued that parents' tendencies to be overprotective and oversolicitous with their ill child represent conscious and unconscious feelings of guilt (Bergman & Lewiston, 1979; Sigal, Chagoya, Villeneuve & Mayerovitch, 1973).

Confusion and even feelings of being unloved have been noted in the well siblings in families where contradictory disciplinary policies toward the ill child and the healthy children are practiced (Poznanski, 1969). Augmented rivalry, jealousy, and resentment are other reactions remarked upon in the healthy children in such families.

Four studies have documented objective changes in parental functioning in families where there is a child afflicted with a chronic disorder. Meyerowitz and Kaplan (1967) present evidence indicating that the parent-sick child pattern of interactions is readjusted (becomes more intensified) in families where there is a child with cystic fibrosis. This is attributed by the authors to the great expenditure of time cystic fibrosis requires parents to spend with their child in home management of the disease. Such a situation is illustrated by the fact that whereas 54% of the 111 mothers in this study had been employed prior to the diagnosis of the disease, only 26% of the mothers were so employed following diagnosis of cystic fibrosis in their child.

Crain and coworkers (1966) also present results of a study which support the notion of changes in parent-child relationships. Examining maternal attitudes and practices toward diabetic and non-diabetic children,

they observe that mothers have a closer expressive relationship with the ill child than with the healthy child. For the diabetic children, mother's expression of warmth and control behavior toward them was significantly correlated with their self esteem and satisfaction with behavior. No significant association occured for these variables with the non diabetic children.

The parent-child association was also studied by Sigal et al., (1973) in 12 families where there was an offspring with a chronic illness and a child not afflicted with illness. Their data indicates that when there is an ill child in the family the parents will foster any combination of the following in this child: failure to promote independence, inability to set limits on the personal habits of the child, and low expectations of the child's performance. This is not the case for healthy children in the family.

Bolstad (1974) compared parental interactions with their orthopedically handicapped and non-handicapped children. No differences were found in their behavioral interactions when the data for mothers and fathers were combined for analyses. However, when the parents' behaviors were examined separately, mothers were significantly more responsive overall and more positive to the handicapped child than to the non-afflicted child.

As already alluded to, in addition to being motivated to alter their relationship with the sick child to avoid feelings of anger and guilt, the need in certain conditions for parents to be actively involved in the treatment regimen of the ill child may also serve to readjust and intensify the bond between them. Routine clinic visits, hospital admissions for tests, surgery, etcetera, prescribed diet and activity

limitations and daily exercise programs all force the parents and child to share inordinate amounts of time and emotionally charged experiences together. Doershuk and Mathews (1968), Vignos (1968), Neill (1968), and Brewer (1968) illustrate this pattern in parents of children with cystic fibrosis, muscular dystrophy, cardiac disease and juvenile rheumatoid arthritis, respectively. Similarly, parents of children with cancer partake in many of these activities with their ill child (Ross, 1978).

Probably as a consequence of these readjustments in the parent-ill child relationship, changed family alliances have also been observed in families with chronically ill children. Poznanski (1969) notes that, in her clinical experience, the mother and the ill child become aligned. She posits that in an attempt to "make it up" to the ill child, increased protection and care are extended by the mother to this child and an intensification of the bond between them may occur. At the same time, the relationship of the mother with her other children may become distorted, due to the extra time and attention the sick child is given. According to Poznanski, the healthy children may interpret this as meaning they are less favored and loved. As described above, the parent-parent relationship may also be affected and the parent who is not as directly involved with the ill child, usually the father, may feel alienated or abandoned by their spouse.

Taylor (1980) provides additional insight into the feelings and experiences of siblings of chronically ill children in response to role realignments. On the basis of her interviews with siblings of medically ill children, she reports that many siblings had feelings of being alone or outside of the family relationships. They saw the parents and the

ill child as dyads which excluded them. Others noted social restrictions because of increased responsibilities at home. Extra domestic chores for well siblings in the family have also been noted by Farber (1959).

Generally then, it seems that the sick child may be privy to a closer, more expressive relationship with the mother as compared to his/her well sibling(s). Crain and colleagues (1966) conclude in this regard, that the "normal" sibling is "handicapped" in the race for growth, attention, and affection.

The comments of several writers which indicate that siblings of children with cerebral palsy (Abrams, 1970), diabetes (Zeidel, 1973), mental retardation (San Martino & Newman, 1974), and chronic disorders in general (Poznanski, 1973) are often deprived of parental attention, further support Crain et al's conclusion. In fact, the term "maternal estrangement", as employed by Roach (1968) - the mother's or mother surrogate's inability to transfer warmth and affection and fulfill the security needs of the developing child--may be a justified descriptor for the relationship between mother and well child in many families where there is a chronically sick youngster.

Reduction and even curtailment of previously characteristic family activities has also been widely reported in the literature on family functioning in relationship to numerous specific disease entities including: leukemia (Oakley & Patterson, 1966), diabetes (Zeidel, 1973), cystic fibrosis (Meyerowitz & Kaplan, 1967), and mental retardation (Schonnel & Watts, 1956-57). Patterns of family life affected entail vacations, visiting, religious activities, and in some cases, even the extracurricular programs of the well children in the household.

Another area of documented disruption in families where there is

a child with a chronic illness is communication patterns. Green (1968) asserts that the lack of communication in families where a child has a nonlife-threatening disease is a striking deficit. The prevalence of poor communication in families where there is a child with a life-threatening disorder can be ascertained from the work of Turk (1964). In Turk's study of families with a child member having cystic fibrosis, breakdown of communication on several levels was observed: between parents, parents and patient, and parents and well children, relatives and neighbors. Sixty percent of the parents interviewed never discussed the diagnosis with the ill child. Parents were also reluctant to discuss the disease with their well children. Most parents in Taylor's (1980) study indicated that they had spoken with their well offspring about the ill children's conditions. However, they also admitted to the infrequency of such discussions and having difficulty finding the time and patience to do it when the need was acute.

Similar observations are offered by Vernick and Karon (1965), Waechter (1971), and Stehbens and Lascari (1974)in their accounts of families of children with cancer.

Peck (1979), in an investigation of the problems experienced by families of long term survivors of leukemia and Wilm's tumor, reveals a particularly interesting observation about altered communication patterns in these families. Not only was communication about the specific disease the afflicted child had stilted, free communication about health issues in general was lacking.

In view of the preceding findings, it is not difficult to comprehend McCollum and Schwartz's (1972) statement that all psychological relationships in the family are influenced by the presence of a child

with a long term medical condition. Disorganization, disruption, and disequilibrium seem to be appropriate adjectives of the changed family dynamics that often occur concomitant to the presence of a chronically sick child. This child, as stated by Koupernik (1973) and Anderson (1981) and demonstrated above, often becomes the permanent epicenter of a disequilibrium. She/he crystallizes the parents' feelings of compassion, pity, over-protectiveness, sympathy,and helpfulness. With this type of imbalance in the whole psychic economy of the family, one should not be surprised to discover that siblings may be frustrated, envious, confused, and furthermore that they may be living in an environment conducive to the development of psychosocial difficulties.

The picture painted is dismal. Most investigators agree that the potential for family dysfunction is quite high, particularly around the time of the diagnosis of chronic illness in a child. However, Venters (1981) and Kupst, Schulman, Honig, Maurer, Morgan, and Fochtman (1982) indicate that family disruption need not be permanent. On the basis of their studies of families of children with cystic fibrosis and cancer, respectively, they offer some differential predictors of good and poor family adjustment. According to Venters, familial sharing of burdens of the stressful situation as well as encouragement to endow the illness situation with a personally significant meaning can strengthen familial interaction and prevent long term family disequilibrium and breakdown. Kupst et al. (1982) also suggest, albeit tentatively, that there is some evidence for the role of support in coping. A good marital relationship and the presence of peer relations for mothers were related to successful coping one year after diagnosis of cancer in a child member of the family.

In summary, though the prevalance of unsophisticated research methodology and the consequential lack of hard data are regretable, four lines of research converge on implicating potential negative effects on sibling adaptation in families with a chronically ill child. These four sources include: (1) studies suggesting sibling maladjustment following the death of their brother or sister; (2) data on the stressfulness of illness of a brother or sister for siblings; (3) preliminary explorations of the impact of childhood chronic illness on siblings; (4) systems literature and research documenting a transformed texture of family life, role realignments, alterations in communication patterns, changes in family routines, and marital disruption where a chronically ill child is present in the family. That siblings can no longer be ignored is obvious. They are living in a family situation which may be harmful to their mental health. The precise nature of this impact, quantification of its magnitude, and identification of those most at risk must now receive attention if the problems of siblings are to be ameliorated and even prevented in the future. Only systematic investigations with a longitudinal framework can adequately address these issues and eliminate some of the ambiguities that presently prevail in the literature.

Variables that may moderate sibling adaptation. Perhaps due to the fact that examination of the adjustment of siblings of chronically ill children is a relatively new phenomenon, few researchers have endeavored to isolate the variables that moderate the adjustment of this population. Nevertheless, certain characteristics of the sibling and features of the illness have received some attention and the findings pertaining to these variables will be discussed below.

a) Age.

Only three studies have considered the age of siblings when investigating their psychosocial adaptation. Findlay, Smith, Graves, & Linton (1969) in a naturalistic observational study of ten families with children attending pediatric specialty clinics observed that the sibling closest in age to the sick child was most affected. However, neither Breslau et al. (1981) or Lavigne and Ryan (1979), in their more methodologically sound studies, found evidence to support the notion that age relationship to the ill child has an important bearing on sibling adjustment. It thus seems as if age is not a particularly relevant moderator variable when considered alone.

However, both Breslau and coworkers and Lavigne and Ryan did document sex x age interactions in their studies, indicating that it is only when age is considered with other demographic characteristics of siblings does its importance emerge. Unfortunately, the findings of these two groups of researchers are not supportive of one another. Whereas the former found that younger male siblings had poorer psychological health than female siblings and that older female siblings were worse off than male siblings, Lavigne and Ryan (1979) reported the reverse. Though differences in measurement instruments and age groups are likely responsible for this discrepancy, future study of these variables and their interaction is necessary.

b) Sex.

Sex differences in reaction to the illness of a brother/sister with a chronic illness have been observed in families of mentally retarded children. Farber (1959) found that female siblings of mentally retarded children displayed more personality problems when the retarded child lived at home, and male siblings had more behavioral problems when the child was institutionalized. In contrast, Gath (1973) found a higher incidence

of anti-social behavior in female siblings of retarded children when compared to a control group and no differences in personality problems. Male siblings did not manifest any differences from controls. Consistent with Farber (1959) but opposed to Gath (1973), Lavigne and Ryan (1979) found a significantly greater incidence of symptomatic behavior in boys on total aggression, irritability and hyperactivity.

The picture becomes more complicated when the work of Tritt (Note 1) and Breslau et al. (1981) are considered. No significant differences in either emotional or behavioral adjustment of siblings of retarded or medically ill children when compared to non-clinical control groups were revealed.

Again, due to these equivocal findings, further exploration of the role of gender of siblings should be undertaken.

c) Characteristics of the illness.

Siblings have been the subject of investigation from the perspective of type of illness in only two studies and the results of each oppose one another. Lavigne and Ryan (1979) found no difference between the four illness groups in their study in aggression, but they did find differences in social withdrawal. They report that the siblings of children with visible illnesses (plastic surgery) were significantly more withdrawn than siblings of patients with invisible illnesses (cardiology and hematology). Breslau et al. (1981) in contrast, found that diagnostic category made no difference to the psychological functioning of siblings despite the fact that they included illness groups in which appearance, i.e., visibility, was affected. Furthermore, whether there is value in differentiating between illnesses with a high probability of fatal outcome and those which are usually nonfatal is unclear at present. Lavigne and Ryan (1979) did not

find support for using this dimension of illness when studying sibling adaptation. However, no other studies have investigated this variable and it would seem premature to drop it from consideration in the future.

The findings of Breslau et al.(1981) and Lavigne and Ryan (1979) show consistency with respect to the variable of severity of illness. Both sets of investigators found that severity did not correspond to the degree of problems noted among siblings. These findings may have been a function of the particular samples they studied, and in spite of the uniformity in results should probably be included in future analysis studying moderators of adjustment.

d) Parental adjustment and level of family functioning.

No formal investigations of the relationship between parents' adaptation or level of family functioning and the adjustment made by siblings have occurred to date. Nevertheless, a number of clinical reports posit the existence of an association between level of family functioning, parental coping,and siblings'adaptation (Binger, 1973; Kaplan et al., 1973; Ross, 1978). Once more, sophisticated study of these potential moderator variables seems warranted.

The literature on variables that moderate the adjustment made by siblings of chronically ill children is sparse and the data that is available is largely equivocal. Clearly, more rigorous examination of the role of each of these variables alone and in combination is required if a more comprehensive understanding of the way they influence sibling adaptation is to be attained.

Summary and conclusions. Relatively few investigators have focused their research efforts on the adaptation of siblings of chronically ill children. A few reports are available but, due to an almost complete deficiency of rigorous studies, it is very difficult to make any but the most tentative statements about their findings. Several of these accounts do coincide in their conclusion that the well siblings of chronically ill children may actually experience many adverse consequences to the stress of long term illness in their brother/sister and receive less support and understanding from their parents and the community at large. For numerous methodological reasons, however, including the following, this conclusion is in need of dire empirical validation. For the most part, there has been a failure to enlist appropriate control groups, adequate sample sizes, and representative subjects. Collection of data where it has occurred, has been largely by means of questionable measuring devices, retrospective interviews with parents and/or physicians and by examination of psychiatric case files. Much of the literature also consists of clinical impressions, observations, and anecdotes which are informative but not a sufficient basis for generalization. Moreover, no longitudinal studies which examine the long term effects of the illness experience exist, and few studies are available which adopt a non-pathology perspective.

An equally serious impediment to deriving valid generalizations about the effects of long term childhood illnesses on siblings relates to the absence of systematic inquiry into the impact of the specific character of the various disease entities. Several relevant dimensions

in this regard include the type of illness, its visibility, severity, stability of prognosis, and whether it is life threatening or not. Other potential moderating variables suggested in the literature are the gender and age of siblings as well as parents' ability to cope and level of family functioning.

It seems best to consider the research undertaken to date as descriptive and preliminary. It has set the stage for future research in its general consensus that chronic illness in a child member of a family often has adverse psychosocial effects on siblings. There is, however, no basis for stating accurately its precise effects. More sophisticated investigations of the impact of the chronic illness experience on this population and of the variables that moderate their adjustment is essential if a comprehensive understanding is to be achieved,and if the siblings who are most at risk for the development of psychosocial difficulties are to be identified. Intervention and prevention strategies will not be formulated and implemented until more rigorous and conclusive evidence is available.

Reference Notes

1. Tritt, S. F. Sibling adjustment in families with institutionalized mentally retarded children: A controlled study. Unpublished Manuscript, 1980.

2. Greer, B. G. On being the parent of a handicapped child. Address given to the Parent Involvement Program. Memphis, Tennessee. April 6, 1974.

3. Paykel, E. S. Life events and acute depression. Paper presented at Annual Meeting of the American Association for the Advancement of Science. Chicago, December, 1970.

4. Pless, I. B. Effects of chronic illness on adjustment: Clinical implications. Paper presented at Behavioral Pediatric Conference, Ottawa, Canada, May 1982.

References

Abrams, R. C. The impact of cerebral palsy on the patient and his family. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Adams, D. W. Childhood malignancy: The psychosocial care of the child and his family. Illinois: Charles C. Thomas, 1979.

Anderson, J. M. The social construction of illness experience: Families with a chronically ill child. Journal of Advanced Nursing, 1981, 6, 427-434.

Anthony, E. J. A working model for family studies. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Anthony, E. J., & Benedek, T. Parenthood - Its psychology and psychopathology. New York: Little Brown & Co., 1970.

Beavers, W. Psychotherapy and growth: A family systems perspective. New York: Bruner-Mazel, 1977.

Bergman, S., Lewiston, N., & West, A. Social work practice and chronic pediatric illness. Social Work in Health Care, 1979, 4 (3), 265-274.

Bibace, R., & Walsh, M. E. Developmental stages in children's conceptions of illness. In G. C. Stone, F. Cohen, & N. E. Adler (Eds.), Health Psychology. San Francisco: Jossey-Bass Publishers, 1980.

Binger, C. M. Childhood leukemia--Emotional impact on siblings. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Binger, C. M., Ablin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. Childhood leukemia: Emotional impact on patient and family. New England Journal of Medicine, 1969, 280 (8), 414-418.

Blum, G. S., & Rosenzweig, S. The incidence of sibling and parental deaths in the anamnesis of female schizophrenics. Journal of Genetic Psychology, 1944, 31, 3-13.

Bolstad, C. A behavioral comparison of handicapped and normal children within the family. Dissertation Abstracts International, 1975, 35, 4160.

Boone, J. E., Baldwin, J., & Levine, C. Juvenile Rheumatoid Arthritis. Pediatric Clinics of North America, 1974, 21 (4), 885-915.

Bowen, M. The use of family theory in clinical practice. Comprehensive Psychiatry, 1966, 7, 345-374.

Breslau, N., Weitzman, H., & Messenger, K. Psychologic functioning of siblings of disabled children. Pediatrics, 1981, 67 (3), 344-353.

Brewer, E. J. Jr., Juvenile rheumatoid arthritis. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Bruhn, J. G. Effects of chronic illness on the family. Journal of Family Practice, 1977, 4 (6), 1057-1060.

Bruhn, J. G., Hampton, J. W., & Chandler, B. C. Clinical marginality and psychological adjustment in hemophilia. Journal of Psychosomatic Research, 1970, 15, 202-215.

Bywater, E. M. Adolescents with cystic fibrosis: Psychosocial adjustment. Archives of Disease in Childhood, 1981, 56, 538-543.

Cain, A. C., Fast, I., & Erickson, M. E. Children's disturbed reaction to the death of a sibling. American Journal of Orthopsychiatry, 1964, 34, 741-752.

Cairns, N. V., Clark, G. M., Smith, S. D., & Lansky, S. B. Adaptation of siblings to childhood malignancy. Journal of Pediatrics, 1979, 95 (3), 484-487.

Caplan, G. Support systems and community mental health. New York: Behavioral Publications, 1974.

Carandang, M. L., Folkins, C. H., Hines, P. A., & Steward, M. S. The role of cognitive level and sibling illness in children's conceptualization of illness. American Journal of Orthopsychiatry, 1979, 49, (3), 474-481.

Coddington, R. D. The significance of life events as etiologic factors in the diseases of children I. A survey of professional workers. Journal of Psychosomatic Research, 1972, 16, 7-18 (a).

Coddington, R. D. The significance of life events as etiologic factors in the diseases of children II. A study of a normal population. Journal of Psychosomatic Research, 1972, 16, 205-213 (b).

Cohen, M. M., & Wellisch, D. K. Living in limbo: Psychosocial intervention in families with a cancer patient. American Journal of Psychotherapy, 1978, 32, (4), 561-571.

Cotter, J. M., & Schwartz, A. D. Psychological and social support of the patient and family. Major Problems in Clinical Pediatrics, 1978, 18, 120-127.

Crain, A. J., Sussman, M. B., & Weil, W. B. Family interaction, diabetes, and sibling relationships. International Journal of Social Psychiatry, 1966, 12, 35-43.

Cytryn, L., Moore, P., & Robinson, M. E. Psychological adjustment of children with cystic fibrosis. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: Impact of disease and death. New York: John Wiley & Sons, 1973.

Davis, F. Passage through crisis: Polio victims and their families. New York: Bobbs-Merrill, 1963.

Davis, R. E. Family of physically disabled child. New York State Journal of Medicine, 1975, 95, 1039-1041.

Debuskey, M. Orchestration of care. In M. Debuskey (Ed.), The chronically ill child and his family, Springfield: Charles C. Thomas, 1970.

Doershuk, C. F., & Mathews, L. W. Cystic fibrosis and obstructive pulmonary disease. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Dorner, S. Adolescents with spina bifida: How they see their situation. Archives Diseases of Childhood, 1976, 51, 439-444.

Ehrlich, R. M. Diabetes mellitus in childhood. Pediatric Clinics of North America, 1974, 21 (4), 871-883.

Eiser, C. Psychological development of the child with leukemia: A review. Journal of Behavioral Medicine, 1979 2 (2), 141-157.

English, R. W. Correlates of stigma towards physically disabled persons. Rehabilitation Research and Practice Review, 1971, 2, 177.

Erikson, E. H. Identity and the life cycle. New York: International University Press, 1959.

Farber, B. Effects of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 1959, 24 (2), 1.

Farber, B. Family organization and crisis: Maintenance of integration in families with a severely mentally retarded child. Monographs of the Society for Research in Child Development, 1959, 25 (1), 1.

Fergusson, J. H. Late psychologic effects of a serious illness in childhood. Nursing Clinics of North America, 1976, 11 (1), 83-93.

Findlay, I. I., Smith, P., Graves, P. J., & Linton, M. L. Chronic disease in childhood: A study of family reactions. British Journal Medical Education, 1969, 3, 66-69.

Ford, A. B., Liske, R. E., & Ort, R. S. Reactions of physicians and medical students to chronic illness. Journal of Chronic Disease, 1962, 15, 785-794.

Forrester, J. W. Principles of systems. Cambridge: Wright-Allen Press, 1968.

Framo, J. L. Symptoms from a family transactional viewpoint. International Psychiatry Clinics, 1970, 7, 125-171.

French, A. Disturbed children and their families. New York: Human Sciences Press, 1977.

Friedman, S. B. General discussion. In G. D. Grave and I. B. Pless (Eds.), Chronic childhood illness; Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service NIH, 1976.

Friedman, S. B. Management of death of a parent or sibling. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Friedman, S. B., Chodoff, P., Mason, J. W., & Hamburg, D. A. Behavioral observations on parents anticipating the death of a child. Pediatrics, 1963, 32, 610-624.

Furman, R. Death and the young child: Some preliminary considerations. Psychoanalytic Study of the Child, 1964, 19, 321-333.

Furman, R. A child's capacity for mourning. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Futterman, E. H., & Hoffman, I. Crisis and adaptation in the families of fatally ill children. In E. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons,1973.

Gardner, J. H., & Radel, M. S. Portrait of the disabled in the media. Journal of Community Psychology, 1978, 269-274.

Gath, A. The school age siblings of mongol children. British Journal of Psychiatry, 1973, 132, 161-167.

Gayton, W. F., Friedman, S. B., Tavormina, J. F., & Tucker, F. Children with Cystic Fibrosis: 1. Psychological test findings of patients, siblings, and parents. Pediatrics, 1977, 59 (6), 888-894.

Golan, N. Treatment in crisis situations. New York: The Free Press, 1978.

Gordon, N. B., & Kutner, B. Long term and fatal illness and the family. Journal of Health and Human Behavior, 1965, 6, (4) 190-196.

Grave, G. D. The impact of chronic childhood illness on sibling development. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education, and Welfare: Public Health Service, NIH, 1976.

Gray, W., & Rizzo, N. D. History and development of general system theory. In W. Gray, and F. J. Duhl, & N. D. Rizzo (Eds.), General system theory and psychiatry. Boston: Little, Brown, 1969.

Green, M. The management of long term nonlife-threatening illnesses. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Green, M., Haggerty, R. J. Introduction. Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968 (a).

Green, M., & Haggerty, R. J. Epidemiology of chronic disease. Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968 (b).

Haley, J. Research on family patterns: An instrument measure. Family Process, 1967, 6, 81-97.

Hamovitch, M. B. The parent and the fatally ill child. City of Hope Medical Center, Duarte,California, 1964.

Harasymis, S., Horne, B., & Lewis, S. A longitudinal study of disability and group acceptance. Rehabilitation Literature, 1976, 37, 98-102.

Harder, L., & Bowditch, B. Siblings of children with cystic fibrosis: Perceptions of the impact of the disease. Children's Health Care, 1982, 10 (4), 116-120.

Hawke, W. A. Impact of cerebral palsy on patient and family. Canadian Nurse, 1967, 63 (1), 29-31. (Abstract)

Heffron, W. A., Bommelaere, K., & Masters, R. Group discussions with parents of leukemic children. Pediatrics, 1973, 52 (6), 831-839.

Holmes, T. H., & Rahe, R. H. The social readjustment rating scale. Journal of Psychosomatic Research, 1967, II, 213-218.

Illingworth, R. S. The increasing challenge of handicapped children. Clinical Pediatrics, 1964, 3, 189-191.

Isaacs, J., & McElroy, M. R. Psychosocial aspects of chronic illness in children. Journal of School Health, 1980 (Aug), 318-321.

Jaffe, N. Late side effects of treatment: Skeletal, genetic, central nervous system and oncogenic. Pediatric Clinics of North America, 1976, 23 (1), 233-244.

Kagan-Goodheart, L. Reentry: Living with childhood cancer. American Journal of Orthopsychiatry, 1977, 47 (4), 651-658.

Kaplan, D. M., Smith, A., Grobstein, R., & Fischman, S. E. Family mediation of stress. Social Work, 1973, 18 (4), 60-69.

Keller, M. Progress in school children in a sample of families in the Eastern Health District of Baltimore, Maryland. Milbank Memorial Fund Quarterly, 1953, 31 (4), 391-400.

Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J., & Rigler, D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. Journal of Pediatrics, 1980, 97 (1), 126-131.

Kelly, O. E. Until tomorrow comes. New York: Everest House, 1979.

Klein, S. D. Chronic kidney disease: Impact on child and family and strategies for coping. (Doctoral dissertation. University of Minnesota, 1975). Dissertation Abstracts International, 1975, 36 (8).

Knapp, V. S., & Hansen, H. Helping the parents of children with leukemia. Social Work, 1973, 18 (4), 70-75.

Korsch, B. M. Outcome data for chronic renal patients. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Korsch, B. M. & Barnett, H. L. The physician, the family, and the child with nephrosis. Journal of Pediatrics, 1961, 58 (5), 707-715.

Korsch, B. M., Negrette, V. F., Gardner, J. E., Weinstock, C. L., Mercer, A. S., Grushkin, C. M., & Fine, R. W. Kidney transplantation in children: Psychosocial followup study on child and family. Journal of Pediatrics, 1973, 83 (3), 399-408.

Koupernik, C. Editorial comment. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Kupst, M. J., Schulman, J. L., Honig, G., Maurer, H., Morgan, E., & Fochtman, D. Family coping with childhood leukemia: One Year after diagnosis. Journal of Pediatric Psychology, 1982, 7 (2), 157-174.

Lansky, S. B., Cairns, N. V., Hassanein, R., Wehr, J., & Lowman, J. T. Childhood cancer: Parental discord and divorce. Pediatrics, 1978, 62 (2), 184-188.

Lavigne, J. V., & Ryan, M. Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 1979, 63 (4), 616-627.

Lawler, R. H., Nakielny, W., & Wright, N. A. Psychological implications of cystic fibrosis. Canadian Medical Association Journal, 1966, 94, 1043-1046.

Levin, S. Nephrotic syndrome in childhood. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Levine, S. Sex-role identification and parental perceptions of social competence. American Journal of Mental Deficiency, 1965-66, 70, 822-824.

Liberthson, E. Helping families live with and for the mentally retarded child. Journal of Rehabilitation, 1968, 34 (6), 21-26.

Linder, R. Mothers of disabled children - the value of weekly group meetings. Developmental Medicine and Child Neurology, 1970, 12, 202-206.

Logan, W. P. D., & Cushion, A. A. Morbidity statistics from General Practice, I. General. London: Her Majesty's Stationery Office, 1958.

Lurie, P. R. Congenital and rheumatic heart disease. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Mattson, A. Long term physical illness in childhood: A challenge to psychosocial adaptation. In R. H. Moos (Ed.), Coping with physical illness. New York: Plenum, 1979.

Mattson, A., & Gross, S. Adaptional and defensive behavior in young hemophiliacs and their parents. American Journal of Psychiatry, 1966, 122, 1349-1356.

Mattson, J. The chronically ill child: A challenge to family adaptation. Medical College Virginia Quarterly, 1972, 8 (3), 171-175.

Mauer, A. M., Simone, J. V., & Pratt, C. B. Current progress in the treatment of the child with cancer. The Journal of Pediatrics, 1977, 91 (4), 523-539.

McAnarney, E.,Pless, J. B., Satterwhite, B., & Friedman, S. B. Psychological problems of children with chronic juvenile arthritis. Pediatrics, 1974, 53, 523-530.

McCollum, A. T., & Gibson, L. E. Family adaptation to the child with cystic fibrosis. Journal of Pediatrics, 1970, 77 (4), 571-578.

McCollum, A. T., & Schwartz, A. H. Social work and the mourning parent, Social Work, 1972, 17 (1), 25-36.

Meyerowitz, J. H., & Kaplan, H. B. Familial response to stress: The case of cystic fibrosis. Social Science and Medicine. 1967, 1, 249-266.

Minde, K., Hackett, J., Killou, D., & Silver, S. How they grow up: 41 physically handicapped children and their families. American Journal of Psychiatry, 1972, 128 (12), 1554-1560.

Minuchin, S. Families and family therapy. Cambridge, Mass.: Harvard University Press, 1974.

Morrissey, J. R. Children's adaptation to fatal illness. Social Work, 1963, 8 (4), 81-88.

Murstein, B. I. The effect of long-term illness of children on the emotional adjustment of parents. Child Development, 1960, 31, 157-171.

Nagera, H. Children's reaction to the death of important objects. The Psychoanalytic Study of the Child, 1970, 25, 360-400.

Neill, C. A. The cardiac child and his family. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Oakley, G. P., & Patterson, R. B. The psychological management of leukemic children and their families. North Carolina Medical Journal, 1966, 4, 186-193.

O'Hara, M. N. Nursing care of the child with respiratory problems. In S. Steele (Ed.), Nursing care of the child with long-term illness. New York: Appleton-Century Crofts, 1977.

O'Malley, J. E., Koocher, G., Foster, D., & Slavin, L. Psychiatric sequelae of surviving childhood cancer. American Journal of Orthopsychiatry, 1979, 49 (4), 608-616.

Peck, B. Effects of childhood cancer on long term survivors and their families. British Medical Journal, 1979, 1, 1327-1329.

Pfefferbaum, B. Pediatric oncology: A review of the changing psychological aspects. International Journal of Psychiatry in Medicine, 1978-79, 9 (3 & 4), 289-296.

Pilling, D. The child with a chronic medical problem - cardiac disorders, diabetes, hemophilia. National Children's Bureau Report. England: NFER Publishing Co., 1973.

Plank, E. Working with children in hospital. Case Western Reserve University, Cleveland, 1962.

Pless, I. B. Epidemiology of chronic disease. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics, Philadelphia: W. B. Saunders Co., 1968.

Pless, I. B. The challenge of chronic illness. American Journal Diseases of Children, 1973, 126, 741-742.

Pless, I. B., & Douglas, J. W. B. Chronic illness in childhood: Part I. Epidemiological and clinical characteristics. Pediatrics, 1971 47 (2), 405-414.

Pless, I. B., & Pinkerton, P. Chronic childhood disorder - Promoting patterns of adjustment. London: Henry Kimpton Publishers, 1975.

Pless, I. B., & Roghmann, K. J. Chronic illness and its consequences: Observations based on three epidemiologic surveys. The Journal of Pediatrics, 1971, 79 (3), 351-359.

Pless, I. B., & Satterwhite, B. A measure of family functioning and its application. Social Science and Medicine, 1973, 7, 613-621.

Pless, I. B., Roghmann, K., & Haggerty, R. J. Chronic illness, family functioning, and psychological adjustment: A model for the allocation of preventive mental health services. International Journal of Epidemiology, 1972, 1, 271-277.

Pollock, G. H. Childhood parent and sibling loss in adult patients. Archives of General Psychiatry, 1962, 7, (4), 295-306.

Poznanski, E. Psychiatric difficulties in siblings of handicapped children. Clinical Pediatrics, 1969, 8 (4), 232-234.

Poznanski, E. Emotional issues in raising handicapped children. Rehabilitation Literature, 1973, 34 (11), 322-326.

Raimbault, G. Psychological problems in the chronic nephropathies of childhood. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Reinhart, J. B. General discussion on impact of chronic childhood illness on sibling development. In G. D. Grave & I. B. Pless (Eds.), Chronic childhood illness: Assessment of outcome. U.S. Department of Health, Education and Welfare: Public Health Service, NIH, 1976.

Rhyne, M. B. Growing up as an atopic child. In M. Debuskey (Ed.), The chronically ill child and his family. Springfield: Charles C. Thomas, 1970.

Richardson, S. A. Patterns of medical and social research in pediatrics. Acta Pediatrica Scandinavica, 1970, 59, 285-272.

Roach, E. G. School underachievement: A psychologists's view. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Robertson, S. Adolescents and dying. Medical Journal of Australia, 1978, 1 (8), 419-421.

Ross, J. W. Social work intervention with families of children with cancer: The changing critical phases. Social Work in Health Care, 1978, 3 (3), 257-271.

Rutter, M., Tizard, J., & Whitmore, K. Education, health and behavior. London: Longmans, Green & Co., 1970.

San Martino, M., & Newman, M. Siblings of retarded children: A population at risk. Child Psychiatry and Human Development, 1974, 4 (3), 168-177.

Satir, V. The family as a treatment unit. In J. Haley (Ed.), Changing families. New York: Grune & Stratton, 1971.

Schiffer, C. G., & Hunt, E. P. Illness among children. Data from United States National Health Survey, Washington, D.C.: U.S. Government Printing Office, 1963.

Schonell, F., & Watts, B. A first survey of the effects of a sub-normal child on the family unit. American Journal of Mental Deficiency, 1956-57, 61, 210-219.

Share, L. Family communication in the crisis of a child's fatal illness: A literature review and analysis. Omega, 1972, 3 (3), 187-201.

Sigal, J. J., Chigoya, L., Villeneuve, C., & Mayerovitch, J. Later psychosocial sequelae of early childhood illness (severe croup). American Journal of Psychiatry, 1973, 130 (7), 786-789.

Solnit, A. J. Who mourns when a child dies? In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Spinetta, J. J., & Maloney, L. J. Death anxiety in the outpatient leukemia child. Pediatrics, 1975, 56, 1034-1037.

Spinetta, J. J., Rigler, D., & Karon, M. Anxiety in the dying child. Pediatrics, 1973, 52, 841-845.

Spock, A., & Stedman, D. J. Psychological characteristics of children with cystic fibrosis. North Carolina Medical Journal, 1966, 27, 426.

Steele, S. General ideas in relation to long term illness in childhood. In S. Steele(Ed.), Nursing care of the child with long term illness. New York: Appleton-Century-Crofts, 1977.

Stehbens, J. A., & Lascari, A. D. Psychological follow up of families with childhood leukemia. Journal of Clinical Psychology, 1974, 30, 394-397.

Steinhausen, H. C., & Schindler, H. P. Psychosocial adaptation in children and adolescents with cystic fibrosis. Developmental and Behavioral Pediatrics, 1981, 2 (3), 74-77.

Swift, C., Seidman, F., & Stern, H. Adjustment problems in juvenile diabetes. Psychosomatic Medicine, 1967, 29 (6).

Tavormina, J. B., Kastner, L. S., Slater, P. M., & Watt, S. L. Chronically ill children: A psychologically and emotionally deviant Population. Journal of Abnormal Child Psychology, 1976, 4, 99-110.

Taylor, S. C. The effects of chronic childhood illnesses upon well siblings. Maternal Child Nursing Journal, 1980 (Sum), 9 (2), 109-116.

Tew, B. & Laurence, K. Mothers, brothers, and sisters of patients with spina bifida. Developmental Medicine and Child Neurology, 1973, 29, 69-76 (Suppl. 29).

Tew, B., Laurence, K., Payne, H., & Rawnsley, K. Marital stability following the birth of a child with spina bifida. British Journal of Psychiatry, 1977, 131, 79-82.

Teyber, E. C., & Littlehales, D. E. Coping with feelings: Seriously ill children, their families, and hospital staff. Children's Health Care, 1981, 10 (2), 58-62.

de Traubenberg, N. R. Psychological aspects of congenital heart disease in the child. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Tropauer, A., Franz, M. N., & Dilgard, V. Psychological aspects of the care of children with cystic fibrosis. American Journal Diseases of Childhood, 1970, 119, 424-432.

Turk, J. Impact of cystic fibrosis on family functioning. Pediatrics, 1964, 34 (1), 67-71.

Venters, M. Familial coping with chronic and severe childhood illness: The case of cystic fibrosis. Social Science and Medicine, 1981, 15A (3), 289-297.

Vernick, J. Meaningful communication with the fatally ill child. In. E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York. John Wiley & Sons, 1973.

Vernick, J., & Karon, M. Who's afraid of death on a leukemic ward? American Journal of Diseases of Childhood, 1965, 109, 393-397.

Vignos, P. J. Management of Duchenne progressive muscular dystrophy. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Waechter, E. H. Children's awareness of fatal illness. American Journal of Nursing, 1971, 71 (6), 1168-1172.

Watson, A. S. The conjoint psychotherapy of marriage partners. American Journal of Orthopsychiatry, 1963, 33, 912-921.

Weil, W. B. Diabetes mellitus. In M. Green & R. J. Haggerty (Eds.), Ambulatory Pediatrics. Philadelphia: W. B. Saunders Co., 1968.

Weiner, J. Reaction of the family to the fatal illness of a child. In B. Schoenberg, A. Carr, D. Peretz, & A. Kutscher (Eds.), Loss and grief: Psychological management in medical practice. New York: Columbia University Press, 1970.

Wolfenstein, M. How is mourning possible? The Psychoanalytic Study of the Child, 1966, 21, 93-123.

Zeidel, A. Problems of emotional adjustment in juvenile diabetes. In E. J. Anthony & C. Koupernik (Eds.), The child in his family: The impact of disease and death. New York: John Wiley & Sons, 1973.

Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. Psychological effects of illness in adolescence. II. Impact of illness in adolescents: crucial issues and coping styles. Journal of Pediatrics, 1980, 97 (1), 132-138.

APPENDIX B

LETTER TO PARENTS OF CHILDREN ATTENDING SPECIALTY MEDICAL CLINICS

THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, CANADA
R3T 2N2

Dear Parents,

Allow me to introduce myself. My name is Sharon Tritt and I am a doctoral candidate in clinical psychology at the University of Manitoba. With the support of the Department of Psychology and the medical staff of the Specialty Clinics at the Children's Centre, I am conducting a research project for my Ph.D. The Project is under the direction of Dr. L. M. Esses, Department of Psychology, Univeristy of Manitoba. The study focuses on the stresses experienced and adaptations required by families in which there is a child member with a chronic illness. The study should provide valuable information which will assist us in determining the concerns of parents and siblings of sick children and possible ways we may help such families deal with their concerns.

The success of this research depends in large part, upon participation of families such as yourselves and would be most appreciated. Your assistance with this study would not require very much of your time and, of course, would be entirely voluntary. _____, the nurse and physician in charge of the Specialty Clinic your child attends, have given their approval for the study. You may wish to discuss your involvement in the project with them.

If you are interested in learning more about the study and possibly participating in it, would you please take a few minutes and answer the questions on the enclosed form including the identifying information (name, address, telephone number). All information provided will be kept confidential. If you express interest in the study, I will contact you by phone within the next couple of weeks to explain more about it and to see whether you and one of your children will be willing to participate. Everyone who fills out the form will be sent a summary of the results once the study is completed.

Please place the completed questionnaire in the enclosed self-addressed, stamped envelope and mail it to me as soon as possible. If you have any questions, feel free to contact me at home at 889-5301 after 6:00 p.m. Thank you very much for your cooperation.

Sincerely,

Sharon Tritt, M.A.
Department of Psychology
University of Manitoba

APPENDIX C

QUESTIONNAIRE FOR FAMILIES WITH A CHRONICALLY ILL CHILD

Appendix C

Whenever possible, for reasons of consistency, it would be appreciated if the mother of the household would fill out the following questionnaire by checking off (✓) the most appropriate response category and answering the other items.

Name of Respondent _____

Address _____

Phone Number _____

1. Occupation

   Mother _____

   Father _____

2. Children

   Number of Children _____

Names of Children	Sex	Age	Grade
_____	___	___	___
_____	___	___	___
_____	___	___	___
_____	___	___	___

2.a. Please place an asterisk (*) by the name of the child in your family with a chronic illness.

3. Employment - For Mothers Only

   Are you currently employed outside the home? Yes____ No____
   When were you last employed outside the home? Date_____

4. How much time do you and your husband spend on a daily basis engaging in treatment related activities with your chronically ill child?

	Less than 1 hour	1-2 hours	3-5 hours	more than 5 hours
Mother	___	___	___	___
Father	___	___	___	___

5. Have the children in your family been informed of what is wrong with your sick child? Yes____ No____

   Comments:

APPENDIX D

LETTER TO FAMILY PHYSICIANS

THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, CANADA
R3T 2N2

Dear Dr._____,

Allow me to introduce myself. My name is Sharon Tritt and I am a doctoral candidate in clinical psychology at the University of Manitoba. With the support of the Department of Psychology and the nursing and medical staff operating specialty clinics at Children's Centre, I am conducting a research project for my Ph.D. The project is under the direction of Dr. L. M. Esses, Department of Psychology, University of Manitoba. The study focuses on the stresses experienced and adaptations required by families in which there is a child member with a chronic illness. It should provide valuable information which will assist us in determining the concerns of parents and siblings of sick children and possible ways in which to help such families deal with their concerns.

The study also involves a control group. As you are probably well aware, such groups are important for comparative purposes and in order to strengthen the results and generalizability of findings. To this end, I would appreciate your assistance. I am looking for twenty seven caucasian, two parent families in which there are two to five children, some of whom are of school age and none of whom are physically, emotionally, or mentally handicapped. I would like to match one child in each of these families with each of the twenty seven children identified by their gender, age, and parental occupational status on the attached sheet.

If possible, I would like you to have your nurse or assistant select all the families from your caseload who match any of the index children and then randomly select one or two for each of the twenty seven children described on the attached sheet. In this way, all twenty seven children with chronically ill siblings will be closely matched with a random sample of control siblings on relevant variables. I would also ask you to address and mail the enclosed letter to this subsample selected by your nurse or assistant.

These letters describe to parents the difficulty of obtaining control groups despite their importance, and ask parents for their assistance with the study. Their cooperation requires the completion of a questionnaire and two in-home interviews of approximately one hour duration. Your sending these letters guarantees the anonymity of those families who are not interested in participating in the study.

If you have any questions, please feel free to contact me at home at 889-5301 after 6:00 p.m. Thank you so much for your cooperation. I will send you a copy of the results of the study including a description of its implications, when my research is complete.

Sincerely,

Sharon Tritt, M.A.,
Department of Psychology
University of Manitoba

APPENDIX E

LETTER TO CONTROL FAMILIES

THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, CANADA
R3T 2N2

Dear Parents,

Allow me to introduce myself. My name is Sharon Tritt and I am a doctoral candidate in clinical psychology at the University of Manitoba. With the support of the Department of Psychology, I am conducting a research project for my Ph.D. The project is under the direction of Dr. L. M. Esses, Department of Psychology, University of Manitoba. The study focuses on the stresses experienced and adaptations required by families in which there is a child member with a chronic illness. The study should provide valuable information which will assist us in determining the concerns of parents and siblings of sick children and possible ways we may help such families deal with their concerns.

In order to assess difficulties that are particular to families in which there is a chronically ill child, it is essential to, at the same time, gather comparative information from families wherein no illness exists. Your family physician is assisting me in identifying such families. He/she has at random, selected eligible participants for a comparison group and distributed this letter to them. I have not been informed of the names of the families to whom these letters have been sent.

It is often difficult to obtain help from families who themselves are not in crisis or in need of supportive services. The success of this research project, however, does depend on the participation of families such as yourselves and would be most appreciated. Your assistance with this study would not require very much of your time and, of course, would be entirely voluntary.

If you are interested in learning more about the study and possibly participating in it, would you please take a few minutes and answer the questions on the enclosed form including the identifying information (name, address, telephone number). All information provided will be kept confidential. Your family doctor will not be informed of your decision regarding participation. If you express interest in the study, I will contact you by phone within the next couple of weeks to explain more about it and to see whether you and your child will be willing to participate. Everyone who fills out the form will be sent a summary of the results once the study is completed.

Please place the completed questionnaire in the enclosed self-addressed stamped envelope and mail it to me as soon as possible. If you have any questions, feel free to contact me at home at 889-5301 after 6:00 p.m. Thank you very much for your cooperation.

Sincerely,

Sharon Tritt, M.A.
Department of Psychology
University of Manitoba

APPENDIX F

QUESTIONNAIRE FOR CONTROL FAMILIES

Appendix F

Whenever possible, for reasons of consistency, it would be appreciated if the mother of the household would fill out the following questionnaire by checking off (✓) the most appropriate response category and answering the other items.

Name of Respondent: _____

Address: _____

Phone Number: _____

1. Occupation

   Mother _____

   Father _____

2. Children

   Number of Children _____

Names	Sex	Age	Grade
_____	___	___	_____
_____	___	___	_____
_____	___	___	_____
_____	___	___	_____

3. Employment - For Mothers Only

   Are you currently employed outside the home? Yes ____ No ____

   When were you last employed outside the home? Date _____

APPENDIX G

TELEPHONE INTERVIEW

Appendix G

Telephone Interview

I would like to speak to Mrs. _____, please. Hello, Mrs. _____. My name is Sharon Tritt and I am with the Department of Psychology at the University of Manitoba. A few weeks ago you filled out a questionnaire I sent you about the study I am doing for my Ph.D. Do you remember this? Thank you very much for taking the time to complete the questionnaire and sending me the information.

At that time you indicated an interest in learning more about the study. If you are still interested and have a few minutes right now, I would like to tell you more about the study (wait for response). What I am interested in studying is children from families in which there is a chronically ill child and children from families in which there are no chronically or otherwise ill children. I would like to learn more about the personal satisfactions, dissatisfactions and various aspects of the adjustment of these children. The findings resulting from the study should provide valuable information regarding the concerns, feelings and behavior of children from these two types of families. Would you be interested in taking about two hours of your and one of your children's time to participate in two interviews for this study, or would you like more information about the study?

Your family's involvement consists of two appointments in your home three months apart, each of which will last for approximately one hour At this time, both you and your husband, and one of your children will

fill out some brief questionnaires and your child will be interviewed. All of the information collected will be kept strictly confidential. A summary of the major results of the study will be sent to you when it is completed. Would you be interested in participating in this study? Good.

Your husband, yourself, and your child, _____, must be present for part of the appointment. When would be a convenient time for all of you? Do you have a piece of paper and a pencil handy? _____, my research assistant, will visit with you on day and date at time. My telephone number is 889-5301, in case you need to reach me before the appointment, and my name again is Sharon Tritt. Do you have any questions? Thank you very much.

APPENDIX H

LETTER TO FAMILIES NOT SELECTED

THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, CANADA
R3T 2N2

Dear

A few weeks ago, you filled out a questionnaire I sent you about a study I am doing for my doctoral degree. Thank you very much for your response. There were many people who were interested in the study, and I have selected a smaller number to inverview for the study. While you were not among those selected, I would like to thank you for your interest. However, I would like to explain to you more about the study at this time.

I am interested in studying some of the personal feelings and concerns of children from families where there is a chronically ill child member and families where there are no chronically ill members. The children from families with a sick child I am studying are families in which the diagnosis of the illness has occurred recently. These children will also be interviewed three months from now, once the reaction of the family to the diagnosis has diminished and the chronicity of the disease has set in. Chronic illness sometimes creates difficult times for all family members, and I am interested in studying how the healthy child members adjust to this process, compared to children who do not live with a sick sibling. Hopefully, this study will provide valuable information about the concerns of children from these two different types of families.

When the study is completed, I will send you a summary of the results. I hope to be able to do this by June of 1983.

If you have any questions about the study, please feel free to contact me at home at 889-5301.

Thankyou again for your interest.

Sincerely yours,

Sharon Tritt
Department of Psychology
University of Manitoba

APPENDIX I

FEEDBACK LETTER TO ALL VOLUNTEERS

THE UNIVERSITY OF MANITOBA

DEPARTMENT OF PSYCHOLOGY

WINNIPEG, CANADA
R3T 2N2

Dear

Several months ago I wrote you a letter explaining a study I was doing for my doctoral degree in psychology at the University of Manitoba. The study was concerned with how the siblings of children with chronic medical illnesses cope with this experience. You indicated that you were interested in learning more about the study and some of you agreed to be interviewed for it. Thank you for your interest and cooperation. The study is now completed and I would like to provide you with feedback about some of the major findings.

I studied two groups of families, namely those in which there was a child member with a chronic medical illness and those in which there were no members with chronic diseases. Since I was interested in interviewing the healthy siblings of children with illnesses, I specified that there had to be at least two children in each family. Twenty seven children and their parents from each of these two groups were interviewed, making a total of 54 families. An attempt was made to choose families in the two groups who were similar to each other in terms of size, age and sex of children, father's occupational and mother's employment status. Statistical analysis confirmed that the groups did not differ greatly or any of these variables and were well matched.

Almost all of the interviews were conducted in the families' homes by a trained interviewer who was an honours student in psychology and me. The children were interviewed and filled out questionnaires dealing with their emotional adjustment, while both their mothers and fathers completed questionnaires regarding the behavioral adjustment of their children and family functioning.

All of the results of the study were analyzed in terms of average differences between the groups as a whole (presence of children with chronic illnesses versus no ill children), not in terms of individual children or families. Therefore, the method of group comparisons utilized in analyzing the results of this study cannot be used to provide you with information about how your own family compared with others.

On the average, the siblings of children with chronic illnesses had very similar levels of self esteem when compared with the siblings of nonsick children. They were, however, somewhat more anxious and boys and girls in this group were found to express their anxiety in different ways than boys and girls from families where there were no medically ill children. The siblings of children with illnesses were also rated by their parents as having more behavior problems and especially in engaging in more behaviors of a shy-anxious nature.

Interviewing the children who had a brother/sister who was sick proved to be very interesting. Though most of these children appeared to be coping very well, many stresses and frustrations of the experience of living with a sick child were identified and an eagerness to discuss this was generally evident. A lot of the younger children expressed some resentment of the extra attention and material objects they perceived as being given to the child who was sick. Many older children also felt this way but could make more sense of the situation intellectually.

There were indications that the amount of time parents spend daily with the child in the family who is sick, the gender and age of the healthy children, the specific type of illness, and whether a family is functioning at a higher or lower level have implications for the adjustment made by the siblings of chronically ill children.

The level of family functioning in the two groups was not significantly different, although parents of chronically ill children did report that more changes had occurred for their families over the course of the two interviews conducted. Likewise, parents with a sick child tended to spend less time in leisure activities with their healthy children and this was especially the case for fathers. Some of the parents of ill children revealed that they were aware that they did not spend a sufficient amount of time with their other children and many expressed a desire for more support from the medical community as well as relatives and friends.

In summary, this study provided very valuable information on both the positive and negative effects on siblings that may result from a sister/brother with a chronic medical illness. Hopefully, this information will be used to offer better services and resources for such families.

Thank you again for your cooperation. If you have any questions about the study, feel free to call me at home in the evening at 889-5301.

Sincerely,

Sharon Tritt, M.A.
Department of Psychology
University of Manitoba

APPENDIX J

BEHAVIOR PROBLEM CHECKLIST

Appendix J

Behavior Problem Checklist

1. Name of child

   _____

2. Age _____

3. Sex _____

4. Name of person completing this checklist

   _____

5. Relationship to child (circle one)

   a. Mother

   b. Father

Instructions:

Please indicate which of the following constitute problems, as far as this child is concerned. If an item does <u>not</u> constitute a problem, encircle the zero; if an item constitutes a <u>mild</u> problem, encircle the one; if an item constitutes a <u>severe</u> problem, encircle the two. Please complete every item.

Appendix J

Behavior Problem Checklist

0 - no problem; 1 - mild problem; 2 - severe problem

0	1	2	1.	Oddness, bizarre behavior
0	1	2	2.	Restlessness, inability to sit still
0	1	2	3.	Attention-seeking, "show off" behavior
0	1	2	4.	Stays out late at night
0	1	2	5.	Doesn't know how to have fun; behaves like a little adult
0	1	2	6.	Self-consciousness; easily embarrased
0	1	2	7.	Fixed expression, lack of emotional reactivity
0	1	2	8.	Disruptiveness; tendency to annoy and bother others
0	1	2	9.	Feelings of inferiority
0	1	2	10.	Boisterousness, rowdiness
0	1	2	11.	Crying over minor annoyances and hurts
0	1	2	12.	Preoccupation; "in a world of his own"
0	1	2	13.	Steals in company with others
0	1	2	14.	Shyness, bashfulness
0	1	2	15.	Social withdrawal, preference for solitary activities
0	1	2	16.	Dislike for school
0	1	2	17.	Jealousy over attention paid to other children
0	1	2	18.	Belongs to a gang
0	1	2	19.	Repetitive speech
0	1	2	20.	Short attention span
0	1	2	21.	Lack of self-confidence
0	1	2	22.	Inattentive to what others say
0	1	2	23.	Easily flustered and confused
0	1	2	24.	Incoherent speech
0	1	2	25.	Fighting

0	1	2	26.	Loyal to delinquent friends
0	1	2	27.	Temper tantrums
0	1	2	28.	Reticence; secretiveness
0	1	2	29.	Truancy from school
0	1	2	30.	Hypersensitivity; feelings easily hurt
0	1	2	31.	Laziness in school and in performance of other tasks
0	1	2	32.	Anxiety, chronic general fearfulness
0	1	2	33.	Irresponsibility, undependability
0	1	2	34.	Excessive daydreaming
0	1	2	35.	Masturbation
0	1	2	36.	Has bad companions
0	1	2	37.	Tension, inability to relax
0	1	2	38.	Disobedience, difficulty in disciplinary control
0	1	2	39.	Depression, chronic sadness
0	1	2	40.	Uncooperativeness in group situations
0	1	2	41.	Aloofness, social reserve
0	1	2	42.	Passivity, suggestibility, easily led by others
0	1	2	43.	Clumsiness, awkwardness, poor muscular coordination
0	1	2	44.	Hyperactivity, "always on the go"
0	1	2	45.	Distractibility
0	1	2	46.	Destructiveness in regard to his own and/or others' property
0	1	2	47.	Negativism, tendency to do the opposite of what is requested
0	1	2	48.	Impertinence, sauciness
0	1	2	49.	Sluggishness, lethargy
0	1	2	50.	Drowsiness
0	1	2	51.	Profane language, swearing, cursing
0	1	2	52.	Nervousness, jitteriness, jumpiness; easily startled
0	1	2	53.	Irritability; hot-tempered, easily aroused to anger
0	1	2	54.	Enuresis, bed-wetting
0	1	2	55.	Often has physical complaints, e.g., headaches, stomach aches

APPENDIX K

SELF-APPRAISAL INVENTORY

GRADES K-3

Appendix K

Self-Appraisal Inventory

Grades K-3

Subject # _____

Name: _____

Sex: _____

Grade: _____

	Yes	No
1. Are you easy to like?		
2. Do you often get in trouble at home?.....		
3. Can you give a good talk in front of you class?....		
4. Do you wish you were younger?		
5. Are you an important person in your family?.....		
6. Do you often feel that you are doing badly in school?		
7. Do you like being just what you are?.....		
8. Do you have enough friends?.....		
9. Does your family want too much of you?.....		
10. Do you wish you were someone else?.....		
11. Can you wait your turn easily?.....		
12. Do your friends usually do what you say?.....		
13. Is it easy for you to do good in school?.....		
14. Do you often break your promises?.....		
15. Do most children have fewer friends than you?.....		
16. Are you smart?		

	Yes	No
17. Are most children better liked than you?.....		
18. Are you one of the last to be chosen for games?....		
19. Are the things you do at school very easy for you?..		
20. Do you know a lot?.....		
21. Can you get good grades if you want to?.....		
22. Do you forget most of what you learn?.....		
23. Do you feel lonely very often?.....		
24. If you have something to say do you usually say it?		
25. Do you get upset easily at home?.....		
26. Do you often feel ashamed of yourself?.....		
27. Do you like the teacher to ask you questions in front of other children?.....		
28. Do the other children in the class think you are a good worker?.....		
29. Are you hard to be friends with?.....		
30. Do you find it hard to talk in your class?.....		
31. Are most children able to finish their school work more quickly than you?.....		
32. Do members of your family pick on you?.....		
33. Are you any trouble to your family?.....		
34. Is your family proud of you?.....		
35. Can you talk to your family when you have a problem?.....		
36. Do you parents like you even if you have done something bad?.....		

APPENDIX L

SELF-APPRAISAL INVENTORY

GRADES 4-6

Appendix L

Self-Appraisal Inventory

Grades 4-6

Subject # _____

Name: _____

Sex: _____

Grade: _____

	Yes	No
1. Other children are interested in me.....		
2. School work is fairly easy for me.....		
3. I am satisfied to be just what I am.....		
4. I should get along better with other children than I do.....		
5. I often get in trouble at home.....		
6. My teachers usually like me.....		
7. I am a cheerful person.....		
8. Other children are often mean to me.....		
9. I do my share of work at home		
10. I often feel upset in school.....		
11. I'm not very smart.....		
12. No one pays much attention to me at home		
13. I can get good grades if I want to		
14. I can be trusted		
15. I am popular with kids my own age		
16. My family isn't very proud of me		

	Yes	No
17. I forget most of what I learn.....		
18. I am easy to like.....		
19. Girls seem to like me.....		
20. My family is glad when I do things with them.....		
21. I often volunteer to do things in class.....		
22. I'm not a very happy person.....		
23. I am lonely very often.....		
24. The members of my family don't usually like my ideas.		
25. I am a good student.....		
26. I can't seem to do things right.....		
27. Older kids like me.....		
28. I behave badly at home.....		
29. I often get discouraged in school.....		
30. I wish I were younger.....		
31. I am friendly toward other people.....		
32. I usually get along with my family as well as I should.		
33. My teacher makes me feel I am not good enough.....		
34. I like being the way I am.....		
35. Most people are much better liked than I am.....		
36. I cause trouble to my family.....		
37. I am slow in finishing my school work..		
38. I am often unhappy.....		

	Yes	No
39. Boys seem to like me.....		
40. I live up to what is expected of me at home.....		
41. I can give a good report in front of the class.....		
42. I am not as nice looking as most people.....		
43. I have many friends.....		
44. My parents don't seem to be interested in the things I do.....		
45. I am proud of my school work.....		
46. If I have something to say, I usually say it.....		
47. I am among the last to be chosen for teams.....		
48. I feel that my family doesn't usually trust me.....		
49. I am a good reader.....		
50. I can usually figure out difficult things.....		
51. It is hard for me to make friends.....		
52. My family would help me in any kind of trouble.....		
53. I am not doing as well in school as I would like to.		
54. I have a lot of self control.....		
55. Friends usually follow my ideas.....		
56. My family understands me.....		
57. I find it hard to talk in front of the class.....		
58. I often feel ashamed of myself.....		
59. I wish I had more close friends.....		
60. My family often expects too much of me.....		

	Yes	No
61. I am good in my school work.....		
62. I am a good person.....		
63. Others find me hard to be friendly with.....		
64. I get upset easily at home.....		
65. I don't like to be called on in class.....		
66. I wish I were someone else.....		
67. Other children think I am fun to be with.....		
68. I am an important person in my family.....		
69. My classmates think I am a poor student.....		
70. I often feel uneasy.....		
71. Other children often don't like to be with me.....		
72. My family and I have a lot of fun together.....		
73. I would like to drop out of school.....		
74. Not too many people really trust me.....		
75. My family usually considers my feelings.....		
76. I can do hard homework assignments.....		
77. I can't be depended on.....		

APPENDIX M

SELF-APPRAISAL INVENTORY

GRADES 7-12

Appendix M

Self-Appraisal Inventory

Grades 7-12

Subject # _____

Name: _____

Sex: _____

Grade: _____

	Yes	No
1. School work is fairly easy for me.....		
2. I am satisfied to be just what I am.....		
3. I ought to get along better with other people.....		
4. My family thinks I don't act as I should.....		
5. People often pick on me.....		
6. I don't usually do my share of work at home.....		
7. I sometimes feel upset while I'm at school.....		
8. I often let other people have their way.....		
9. I have as many friends as most people.....		
10. Usually no one pays much attention to me at home.....		
11. Getting good grades is pretty important to me.....		
12. I can be trusted as much as anyone.....		
13. I am well liked by kids my own age.....		
14. There are times when I would like to leave home.....		

	Yes	No
15. I forget most of what I learn.....		
16. My family is surprised if I do things with them.....		
17. I am often not a happy person.....		
18. I am not lonely very often.....		
19. My family respects my ideas.....		
20. I am not a very good student.....		
21. I often do things that I'm sorry for later.....		
22. Older kids seem to like me.....		
23. I sometimes behave badly at home.....		
24. I often get discouraged in school.....		
25. I often wish I were younger.....		
26. I am usually friendly toward other people.....		
27. I don't usually treat my family as well as I should..		
28. My teacher makes me feel I am not good enough.....		
29. I always like being the way I am.....		
30. I am just as well like as most people.....		
31. I cause trouble to my family.....		
32. I am slow in finishing my school work.....		
33. I often am not as happy as I would like to be.....		

	Yes	No
34. I am not as nice looking as most people.....		
35. I don't have many friends.....		
36. I feel free to argue with my family.....		
37. Even if I have something to say, I often don't say it.		
38. Sometimes I am among the last to be chosen for teams.		
39. I feel that my family always trusts me.....		
40. I am a good reader.....		
41. It is hard for me to make friends.....		
42. My family would help me in any kind of trouble.....		
43. I am not doing as well in school as I would like to..		
44. I find it hard to talk in front of the class.....		
45. I sometimes feel ashamed of myself.....		
46. I wish I had more close friends.....		
47. My family often expects too much of me.....		
48. I am not very good in my school work.....		
49. I am not as good a person as I would like to be.....		
50. Sometimes I am hard to make friends with.....		
51. I wish I were a different person.....		

		Yes	No
52.	People don't usually have much fun when they are with me.....		
53.	I am an important person to my family.....		
54.	People think I am a good student.....		
55.	I am not very such of myself.....		
56.	Often I don't like to be with other kids.....		
57.	My family and I have a lot of fun together.....		
58.	There are times when I feel like dropping out of school.		
59.	I can always take care of myself.....		
60.	Many times I would rather be with kids younger than me.		
61.	My family doesn't usually consider my feelings.....		
62.	I can't be depended on.....		

APPENDIX N

THE WHAT I THINK AND FEEL QUESTIONNAIRE

Appendix N

What I Think and Feel Questionnaire

Name:_____ Age:_____ Sex:_____

1.	I have trouble making up my mind.	Y	N
2.	I get nervous when things do not go the right way for me.		
3.	Others seem to do things easier than I can.	Y	N
4.	I like everyone I know.	Y	N
5.	Often I have trouble getting my breath.	Y	N
6.	I worry a lot of the time.	Y	N
7.	I am afraid of a lot of things.	Y	N
8.	I am always kind.	Y	N
9.	I get mad easily.	Y	N
10.	I worry about what my parents will say to me.	Y	N
11.	I feel that others do not like the way I do things.	Y	N
12.	I always have good manners.	Y	N
13.	It is hard for me to get to sleep at night.	Y	N
14.	I worry about what other people think of me.	Y	N
15.	I feel alone even when there are people with me.	Y	N
16.	I am always good.	Y	N
17.	Often I feel sick in my stomach.	Y	N
18.	My feelings get hurt easily.	Y	N
19.	My hands feel sweaty.	Y	N
20.	I am always nice to everyone.	Y	N
21.	I am tired a lot.	Y	N
22.	I worry about what is going to happen.	Y	N
23.	Other children are happier than I.	Y	N
24.	I tell the truth every single time.	Y	N
25.	I have bad dreams.	Y	N
26.	My feelings get hurt easily when I am fussed at.	Y	N
27.	I feel someone will tell me I do things the wrong way.	Y	N
28.	I never get angry..	Y	N
29.	I wake up scared some of the time.	Y	N
30.	I worry when I go to bed at night.	Y	N
31.	It is hard for me to keep my mind on my schoolwork.	Y	N
32.	I never say things I shouldn't	Y	N
33.	I wiggle in my seat a lot.	Y	N
34.	I am nervous.	Y	N
35.	A lot of people are against me.	Y	N
36.	I never lie.	Y	N
37.	I often worry about something bad happening to me	Y	N

APPENDIX O

SEMI-STRUCTURED INTERVIEW

Appendix O

Semi-Structured Interview

Before we start let me tell you a little bit about my prc
I have been talking to a number of children who have a brother or sister who has some type of long term illness. I am interested in knowing what it is like to live everyday with a person who has a health problem. I am going to ask you some questions about yourself and your family. Answer them as best you can. What you share with me may be used to help prepare other children to live with their sick brother or sister. I will not tell anybody you know, your parents, brothers, sister, or friends - anything you tell me.

Do you know why your brother/sister goes to the Children's Hospital to visit the doctor? (Elaborate)

_____

_____

_____

Has your brother/sister changed with the disease? If yes, what kinds of changes have occurred? Yes _____ No _____

_____

_____

_____

Do you think that your parents often worry about your brother's/sister's health. If yes, what kinds of things do they worry about? Yes___ No___

_____

_____

_____

Who takes care of your brother/sister the most? What do they do for him/her?

_____

_____

_____

Do you think that your brother/sister gets "special treatment"? Yes___ No___
If Yes, elaborate

_____

_____

_____

	Yes	No
Do you ever feel jealous of your brother/sister?.....		
Is your brother/sister hard to get along with?.....		
Has your brother's/sister's sickness caused your family any problems? (Elaborate).....		

Who in your family do you think has given up the most because of your brother's/sister's illness? _____ Why? _____

Who in the family has been most disturbed and unhappy because your brother/sister is sick? _____.

Have members of your family had to help out extra because your brother/sister is sick? Yes____ No____

Elaborate: Who _____

How _____

How has your brother's/sister's illness affected your life?

Negative: _____

Positive: _____

Have you made any gains by having a sick brother or sister?

Yes_____ No_____ (Elaborate)

Do you have any advice for other children who recently found out that their brother/sister has an illness such as Diabetes/JRA/Gastrointestinal problem?

Do you have any other comments or questions?

APPENDIX P

FAMILY FUNCTIONING INDEX

Appendix P

Family Functioning Questionnaire

1. What sorts of things do you do as a family

   a. In the evenings:

   b. On the Weekends:

   c. On vacations:

   (Put a check (✓) in the box corresponding to your choice)

2. How do you think the children get along together compared with other families? (Disregard if only one child) ___ better ___ same ___ worse

3. Do the children find it easy to talk to their father about their problems? ___ yes ___ sometimes ___ no

4. Do you find your husband an easy person to talk to when something is troubling you? ___ yes ___ sometimes ___ no

5. Is your husband able to spend a lot of time with the children in the evening? ___ yes ___ sometimes ___ no

6. Is your husband able to spend a lot of time with the children on the weekend? ___ yes ___ sometimes ___ no

7. Would you say, all in all, that your family is happier than most other you know, about the same, or less happy? ___ happy ___ same ___ less happy

8. What would you say was the most important problem you as a family had to deal with this last year?

   a. Was a solution arrived at? ___ yes ___ no

   b. Did you discuss the problem with your husband? ___ yes ___ no

   c. Was everyone satisfied with the solution? ___ yes ___ no

9. In every family someone has to decide such things as where the family will live and so on. Many couples talk about such things with the family first, but the final decision often has to be made by the husband or the wife. If these are situations you have not decided on recently, how would they be decided on should they occur. (Write in the number corresponding to your choice.)

1 = Husband always
2 = Husband more than wife
3 = Husband and wife exactly the same
4 = Wife more than husband
5 = Wife always

a. Who usually makes the final decision about what kind of car to get? _____

b. about whether or not to buy some life insurance? _____

c. about what house or apartment to take? _____

d. about what job your husband should take? _____

e. about whether or not you should go to work, or quit work? _____

f. about how much your family can afford to spend per week on food? _____

g. about what doctor to have when someone is sick? _____

h. about where to go on vacations? _____

10. Thinking of marriage in general, which one of these five things would you say is the most valuable part of marriage? (Write in the number corresponding to your choice, using each number only once.)

1 = The chance to have children

2 = The standard of living - the kind of house, clothes, car and so forth

3 = The husband's understanding of the wife's problems and feelings

4 = The husband's expression of love and affection for the wife

5 = Companionship in doing things together with the husband

a. the most valuable part of marriage _____

b. the next most valuable _____

c. third most valuable _____

d. fourth most valuable _____

e. fifth most valuable _____

11. Of course, most couples differ sometimes over things, when you and your husband differ about something, do you usually give in and do it your husband's way or does he usually come around to your point of view?

Husband's way 50/50 Wife's way

12. Would you say disagreements in your household come up more often, about the same, or less often than in other families you know?

More often Same Less often

13. Would you say that compared to most families you know, you feel less close to each other, about the same or closer than other families do?

Less close Same Closer

14. The following are some feelings you might have about certain aspects of marriage. (Write in the number corresponding to your choice.)

1 = Pretty disappointed. I'm really missing out on that.

2 = It would be nice to have more.

3 = It's all right. I guess - I can't complain.

4 = Quite satisfied - I'm lucky the way it is.

5 = Enthusiastic - it couldn't be better.

a. How do you feel about your standard of living, the kind of house, clothes, car and so forth? _____

b. How do you feel about the understanding you get of your problems and feelings? _____

c. How do you feel about the love and affection you receive? _____

d. How do you feel about the companionship of doing things together? _____

15. When your husband comes home from work, how often does he talk about things that happened there? _____ very often _____ sometimes _____ never

APPENDIX Q

TIME SPENT WITH CHILDREN

Appendix Q

Amount of Time Spent with Ill Child

1. Can (ill child) engage in the following activities alone?

	Yes	No
toilet		
dressing		
feeding		

2. What treatment procedures do you (both mother and father) engage in daily with (ill child) ?

List: _____
_____
_____
_____

3. How much time to these activities require on a daily basis by each of you?

Mother _____

Father _____

4. How much time do you spend daily in other than treatment activities with (ill child) ?

_____

5. What do you do together? _____
_____
_____

6. What types of things do you do with the healthy children in your family? _____
_____

7. How much time do you spend together daily? _____

8. Do you ever feel that you do not spend sufficient time with your healthy children? Yes_____ No_____

If Yes: Always_____ Often_____ Sometimes_____ Never_____

APPENDIX R

ACTIVITIES OF DAILY LIVING

Appendix R

Activities of Daily Living Assessment

Name: _____ Age: _____

Key: 1. Completely dependent
2. Moderate assistance
3. Minimal assistance
4. Independent

FEEDING:DRINKING	Comments
Finger feeding	
Eat with spoon	
Fork	
Cut with knife	
Butter bread	
Knife and fork	
Drink with - straw	
- glass	
- cup	
Aids:	

DRESSING	Comments
Shirt/blouse/card	
Jacket/coat	
T.Shirt/undershirt	
Sweater	
Dress	
Slacks/skirts/o-pants	
Underwear	
Shoes/Lace & Tie	
Buttons/Hooks/Buckles	
Zipper	
Mittens	
Hat	
Tucking in clothes	
Braces/splints	
Aids:	

TOILETING	Comments
Toilet-trained	
Independent on and off	
Stand/sit alone	
Manage paper	

PERSONAL CARE	Comments
Brush/comb hair	
Brush teeth	
Squeeze toothpaste	
Taps on and off	
Control temperature	
Wash/dry hands/face	
Wash hair	
Blow nose	
Deodorant/powder	
Razor	
Sanitary Pads	
Bathing independence	
Aids:	

Transfers/w. chair manage	Comments

RECREATIONAL INTERESTS	Comments

HOME SKILLS/SOCIAL SKILLS	Comments
Turns taps	
Open/shut door	
Switches	
Carry things	
Make bed	
Dust/sweep	
Wash/dry dishes	
Pour hot/cold liquids	
Manage stove	
Peel fruit/vegetables	
Set table	
Prepare simple meal	
Wash/iron clothes	
Use sewing machine	
Telephoning	
Write/print/type	
Handling money	
Shopping	
Time Knowledge	
Good grooming	

APPENDIX S

INTERVIEW CONSENT FORM

Appendix S

Interview Consent Form

I am conducting a study to find out how having a chronically ill sibling affects the healthy children in the family.
I would like to interview you and (your child) and administer some brief questionnaires to both of you. In using the information that you and (your child) decide to give me, I will not identify you. All information will be kept entirely confidential. I will observe your privacy and rights.

I hope you will agree to participate in the study and provide your permission for me to interview (your child) . You are free to withdraw at any time during the interview if you so desire.

_____
Interviewer

_____
Date

I understand the purpose of this study and know that my privacy and that of my child will be respected by the interviewer. I also understand that I will be sent a letter describing the outcome of the study once it is finished and that I will not be given information regarding how my family compares with others on an individual level or how my child performed on a certain test.

_____
Parents' Signature

_____
Date

APPENDIX T

SECOND INTERVIEW QUESTIONS

Appendix T

Second Interview Questions

1. Has anything changed for any members of your family since I was here for the first interview? (jobs, deaths, school, accomplishments, etcetera).

2. Has anything become more difficult to handle?

3. Has anything become easier to handle?

*4. Are there times when you feel that you could use more support? (Please elaborate - From whom? When? What kind of support?)

Note. *Only directed to families with a chronically ill child.