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I am submitting herewith a dissertation written by Marilyn E. Smith entitled "Protective Shield: A Thematic Analysis of the Experience of Having an Adult Sibling With Insulin Dependent Diabetes Mellitus." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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PROTECTIVE SHIELD: A THEMATIC ANALYSIS OF THE EXPERIENCE OF HAVING AN ADULT SIBLING WITH INSULIN DEPENDENT DIABETES MELLITUS

A Dissertation

Presented for the

Doctor of Philosophy Degree

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Marilyn E. Smith

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DEDICATION

To my husband,

Edward H. Smith,

for his love and unending support.

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I am most indebted to all my participants, who took the time to share with me their personal experiences and feelings. The opportunity to talk to them made this a mutual project and I can only hope that this study truly reflects their narratives.

To my committee I am genuinely grateful for their time, guidance, and support. I especially wish to thank the chairperson of my committee, Sandra Thomas, for both her confidence in me and her patience with me. She guided my work as well as shaped it and edited it as few can. I am sincerely grateful to Howard Pollio for his personal interest in my work and in me as a person. With his help my personal growth paralleled the progress of this study. I am also very thankful to Carol Smucker, who encouraged me through the dark and lonely moments of this project. I am grateful for Lee Humphreys's enthusiasm for phenomenology, and for helping me to feel that what I was doing was valuable and worthwhile. I will always remember the kindness and compassion I received from Mitzi Davis and Pat Droppleman.

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ABSTRACT

The purpose of this investigation was to describe the adult well sibling's experience of having grown up with a sibling having insulin dependent diabetes mellitus (IDDM). Using existential-phenomenological interview procedures, fourteen participants were asked what it was like to have a chronically ill sibling. Analysis of participants' experiences was done using a herméneutical approach. Data analysis occurred in both the phenomenological research group and individually by the researcher.

The thematic description of the experience of having lived with a chronically ill sibling with IDDM was divided into two interdependent and interrelated periods, the past and the present. The metaphor of a protective shield woven around the diabetic sibling by his or her family, was taken from the words of a participant, and is seen by participants as occurring in the past and the present. The themes of the past provide the background for the themes of the present. Many of the themes of the past are moved forward to the present, but because of the passage of time, are described differently by participants. The themes of the past were: 1) Changes (family patterns, sibling relationship), 2) Wondering how the ill sibling became ill, 3) Jealousy/feeling sorry, 4) Preferential treatment of ill sibling, and 5) Feeling scared/alone. The themes of the

present were: 1) Changes (relationship with sibling and mother), 2) Worry/ responsibility without power, 3) Empathy/sadness/guilt,4) Burdened, and 5) Can't talk about feelings.

Results were discussed with reference to previous studies and theories. Implications for nursing were discussed and suggestions were made regarding future research.

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CHAPTER I

INTRODUCTION

When a trout rising to a fly gets hooked on a line and finds himself unable to swim about freely, he begins with a fight which results in struggles and splashes and sometimes an escape. Often, of course, the situation is too tough for him.

In the same way the human being struggles with his environment and with the hooks that catch him. Sometimes he masters his difficulties; sometimes they are too much for him. His struggles are all that the world sees and it naturally misunderstands them. It is hard for a free fish to understand what is happening to a hooked one.

Karl A. Menninger

Aim of the Study

The chronic illness of a child can create many changes for the entire family, including the healthy siblings. Chronic illness is defined by Jessop and Stein (1988) as "one that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaptation in function. . . in children as lasting 3 months or more in 1 year or requiring at least 1 month of hospitalization" (cited in Jackson, 1992). Using this definition Jackson (1992, p.3) estimates that there are 7.5 million children less than 18 years of age in the United States who have a chronic health condition, with 10% to 15% of these classified as severe.

Among married households with children, the average number of children is 1.90 for blacks, 1.87 for whites, and 2.18 for Hispanics (Fractional Families, 1992). Thus, one

may assume that there are a great number of well children living with chronically ill siblings. Because a problem in any one member of a family may have an effect on all other members of the family system (Mahon, 1992), the chronic illness of a child will likely affect all family members, including the well siblings.

Having a child with a chronic illness constitutes a series of stressors for family members. Such stressors include decreased social support (Hamlett, Pellegrini, & Katz, 1992), decreased family satisfaction (Gayton, Friedman, Tavormina, & Tucker, 1977), severe financial strain (McCollum ,1971), increased communication difficulties (McKeever, 1983), and disorganization of family routine (Boyce et al, 1977).

In addition to such family stressors are the cultural attitudes, stereotypes, and discrimination towards the chronically ill which all members of the family experience. To determine parents' perception of the discrimination towards their chronically ill child Turner-Henson, Holaday, Corser, Ogletree, and Swan (1994) conducted a descriptive survey of 365 parents. Parents were asked to complete the Medical Questionnaire developed by Holaday and Turner-Henson (1991) which included questions on discrimination. Children in the sample were between the ages of 10-12 years of age and had various chronic illnesses, including asthma, congenital heart disease, neuromuscular disorders, diabetes,

seizure disorders, renal disorders, juvenile rheumatoid arthritis/systemic lupus, sickle cell anemia/blood disorders, cystic fibrosis, and growth hormone disorders. It was found that 35% of the parents perceived they, and their children, experienced problems with discrimination. Although discrimination was found to originate in a variety of sources the most common source (55%) originated within the schools. Parents reported problems with children being excluded from school activities, school personnel unwilling to provide special care, exclusion from school field trips, and ridicule/cruelty by peers. Parents also reported discrimination originating from organized groups, such as Scouts and Little League.

The present study focused on the long-term impact on well siblings and the challenges of having a chronically ill child in the family. For the well sibling of a chronically ill child, a unique set of stressors has been recognized. Some of these stressors include social isolation (Taylor, 1980), emotional deprivation (Kramer, 1984), negatively altered peer group (Iles, 1979), increased responsibility (Gallo, Breitmayer, Knafl, and Zoeller, 1991), and fear regarding one's own health (Menke, 1987). Despite experiencing similar stressors resulting from the chronic illness in the family, well siblings of chronically ill children report having varying experiences that are perceived as both positive and/or negative. Positive

perceptions, reported by parents and/or well siblings, have included increased nurturing, cooperation, sensitivity (Taylor, 1980), compassion (Ferrari, 1984; Taylor, 1980), empathy, respect, (Iles, 1979), personal maturation (Ferrell et al., 1994; Kramer, 1984), and family cohesion (Ferrari, 1984; Kramer, 1984). Negative perceptions reported included disruption of interpersonal relationships and routines (Iles, 1979), jealousy (Ferrell et al., 1994; Taylor, 1980) increased competition, increased sibling rivalry, anger, hostility, social withdrawal, decreased school performance (Taylor, 1980), fear of their own death (Walker, 1988), and increase in somatic complaints (Ferrari, 1984).

These results clearly document the stressors of the well siblings and some of the negative and/or positive perceptions which the ill siblings may experience as children. Does the experience of having grown up with a chronically ill sibling result in any long term effects on well siblings as they enter adulthood? Definitive answers to this question are not available in extant literature. It is recognized that a crisis can either present an opportunity for personal growth or increase one's vulnerability to disorder (Younger, 1991). If one considers growing up with a chronically ill sibling as a type of crisis, what will determine if the well child emerges into adulthood with a positive vs negative meaning of the experience?

Long term outcomes have been related to one's perception of the crisis, the number of resources available, and/or one's choice, and use, of specific coping strategies (Holaday, 1984). Is it this set of criteria that will determine the meaning of the experience for the well sibling of a chronically ill child? Or is there something more that needs to be learned that influences the well sibling's perception of the experience of growing up with a chronically ill child?

Five different studies (Gerace, Camilleri, & Ayres, 1993; Gogan, Koocher, Foster, & O'Malley, 1977; Lively, Friedrich, & Buckwalter, 1995; Main, Gerace, Camilleri, 1993; and Martinson & Campos, 1991) used the adult sibling as the source of information to determine the long term outcomes a child's chronic illness has on the well siblings. Findings of the long-term impact on the well siblings in these studies included 1) harboring inappropriate guilt feelings (Gogan et al., 1977), 2) unreasonable feelings of responsibility and powerlessness (Gerace, Camilleri and Ayres, 1993), 3) withholding information from others concerning the nature of their sibling's illness (Main, Gerace and Camilleri, 1993), and 4) increased distancing in all family relationships (Lively, Friedrich, and Buckwalter, 1995). All five studies used a semi-structured interview, involving predetermined questions. One questions if this

type of approach will lead to an understanding of the experience of growing up with a chronically ill sibling.

As a result of the dearth of information concerning both the long term impact a child's chronic illness may have on well siblings and what this experience meant to the well siblings, it was concluded that a study would be done using the qualitative methods characteristic of existential-phenomenology. This group of methods aims at uncovering the basic structures of human existence by seeking to describe themes that constitute the experience (Polkinghorne, 1983).

This researcher acknowledges that differing stressors on the well siblings may occur depending on the diagnosis of the ill child. Different chronic illnesses may predispose siblings to different psychosocial outcomes (Ferrari, 1984). For the purpose of this study, therefore, the specific chronic illness that was researched was Type I, or insulin-dependent, diabetes mellitus (IDDM). IDDM is the most common metabolic disorder of childhood and, according to LaPorte and Cruickshanks (cited in Grey, 1992), affects 1 child in every 600. It is the fifth leading cause of death in the United States and reduces life expectancy of a child to 44 years of age. The etiology of IDDM is unknown, although genetic susceptibility is known to be a necessary precursor (Grey, 1992).

It was proposed by this researcher that a study of the adult well sibling's experience of a common childhood

chronic illness would give some understanding of the long-term impact a chronic illness may have on the life of the well siblings of the family. Thus, the aim of this study was to describe the adult well sibling's experience of having grown up with a sibling having IDDM.

Perceived Justification for Studying the Phenomenon

After reviewing the literature surrounding the well sibling's experience of growing up with a chronically ill child, and in listening to the stories of adults who grew up with a chronically ill sibling, one is struck by the paucity of research about such common experiences. Such a lack of knowledge provided the impetus for conducting further research, particularly of a qualitative nature, in order to elicit an understanding of the experience of growing up with a chronically ill sibling. The aim of this research was to discover what it meant to grow up with a chronically ill sibling, and what perceptions of this experience were brought into adulthood. Such knowledge may assist nurses to know if, when, and how they can intervene in families who have both chronically ill and well children.

Researcher Assumptions and Biases

Assumptions of this researcher concerning all families, and families of chronically ill children, include:

1) Families are systems in which the behaviors of one member influence the behaviors of other members.

2) Self esteem of a child is influenced by parental behaviors.

3) Each family member has an assigned role within the family.

4) All families have rules that govern family and individual behavior.

5) All children need to feel respected and unique.

6) Families are part of a larger social system which includes churches, communities, and schools.

7) Any one family member exerts influence on his or her relationship with every other family member (Powell & Ogle, (1985) (e.g. parent will influence the interaction between sisters).

8) Children need a continuous information system that is direct, honest, and age appropriate.

9) Having a child with a chronic illness changes the family.

10) A number of situational factors may influence the impact of the chronic illness on an individual (e.g. number of siblings in family, financial or educational status of family).

Experiential Context

The researcher's interest in the present phenomenon results from both personal and professional experiences with well siblings of chronically ill children. As a parent,

having had a child, at the age of 10, suddenly develop a life-threatening chronic illness created many difficulties for our family. The potential impact this experience could have on the other four well siblings was not recognized for many months after the initial symptoms of the illness. This recognition occurred when one of the well siblings asked if their ill sibling was going to die. It was this question that made me reflect upon what, if any, long-term consequences this experience could have on the well children.

I have also observed in my nursing practice that the experiences of the well sibling of a child with a chronic illness can still vividly and emotionally be recalled in adulthood. For example, in group therapy for hospitalized psychiatric patients, a middle-aged woman expressed resentment of her mother for showing her chronically ill sibling more attention than she felt she received. I have also spoken with non-psychiatric adults who have shared their experiences of having grown up with a chronically ill sibling, and the individuals felt that the experience had both a negative and a positive impact on them.

Selected Qualitative Research Method

The qualitative method of existential-phenomenology was used in the present study to gain an understanding of the experience of growing up with a chronically ill sibling. Phenomenology is guided by the phenomena, following the path

of individual experiences (Heidegger, 1950/1970). Phenomenology attempts to describe the lived experience of an individual through his/her perceptions of the experience (Merleau-Ponty, 1956). Merleau-Ponty (Langer, 1989) believed that "all knowledge takes place within the horizons opened up by perception" (p. xv). A perception, for Merleau-Ponty, is "the background from which all acts stand out, and is presupposed by them" (Zaner & Ihde, 1973,p.76). Merleau-Ponty further explains that "to seek the essence of perception is to declare that perception is, not presumed true, but defined as access to truth" (Zaner & Ihde, 1973, p.82). Thus, the goal of phenomenology is to describe the experience of a given phenomenon as it is experienced by the participants not as it fits a theory or the researcher's expectations.

The importance of describing lived experience, as a research method, is recognized by many researchers: for example, Boyd (1993) states that "people, in all their subjectivity, are inseparably caught up in the physical world in such a way that the truth we search for in nursing research efforts will be grasped only by attending to the realities constituted in individual experiencing" (p. 104). Through existential-phenomenology an understanding of the experience of having grown up with a chronically ill sibling will be sought.

Origin of Existentialism

Soren Kierkegaard (1813-1855) is acknowledged as the founder of existentialism. Resisting an atomistic way of looking at people, Kierkegaard spoke of consciousness in terms of human existence. Kierkegaard conceived a person's existence, "as a subject-in-relationship-to-God. . . only authentically himself in relation to the God of Revelation." For Kierkegaard existence is "absolutely original and irrepeatable, radically personal and unique" (Luijpen, 1969, p.31-32). His attention was directed primarily to the description of human action rather than to human knowledge (Solomon, 1980).

The existentialists were a diverse group whose thoughts ranged from Kierkegaard's intensely religious views to Sartre's denial of the existence of God and of all spiritual reality (Lescoe, 1973). They did share some common themes, though, which included: 1) an insistence of the return to the study of the individual human being, 2) a preoccupation with the question of an authentic and meaningful existence, 3) a belief in absolute individual freedom, and 4) the treatment of fellow human beings as individuals who have personal rights and dignity that must be respected (Lescoe, 1973).

For existentialism absolute freedom was an important concept. Although existentialists believed that a person had the freedom to decide to do anything, they believed that

absolute freedom was free only within the boundary of one's situation. Existentialism insists that "men are always in a position such that they must make choices; but we must not forget that existentialism also insists that men are always in a position such that there are any number of choices that they do not have" (Solomon, 1980, p. 37). According to Langer (1989) "the existentialist philosophers' central concern is to prompt humans not to live thoughtlessly but rather, to have a keen awareness of their freedom and responsibility in the shaping of a situation in which they are always already involved" (p. ix).

Origin of Phenomenology

Phenomenology originated with the German philosopher Edmund Husserl (1859-1938) "as a new approach to philosophy based on a description of immediate experiences with all its biases" (Watson & Evans, 1991, p. 504). Husserl's phenomenology was a response to positivism, a science based on scientific facts. According to Hammond, Howarth and Keat (1991) Husserl believed that "the positivist limitation of knowledge to the facts. . . excluded value questions from the realm of rational enquiry, and more generally excluded philosophy itself" (p.9). For Husserl, phenomenology was the study or description of phenomena, and "a phenomenon is simply anything that appears or presents itself to someone. . . phenomenology involves the description of things as one experiences them, or of one's experiences of things"

(Hammond et al., 1991, p.1). Husserl's phenomenology investigates the nature of human consciousness and the essences (meaning) of the experience, that "what makes a thing what it is" (Solomon, 1980, p.27). According to Husserl (1952/1989) "it is one thing to be conscious at all that the sky is blue, and it is another thing to live in the performance of the judgment (that the sky is now blue) in an attentive, explicitly grasping, specifically intentional way" (p. 5).

Husserl valued the everyday experiences of people. He believed, though, that these experiences had to be seen within their context. Husserl (1952/1989) noted that

> lived experiences are not given to us in experience as annexes, lacking internal connection of material Bodies, as if they were unified with one another only through the common phenomenal link to the Body. Instead, they are one by means of their very essence; they are bound and interwoven together, they flow into one another in layers and are possible only in this unity of a stream. Nothing can be torn away from this stream; nothing can be separated off as, so to say, a thing for itself. (p. 98)

Thus, the guiding principle of the phenomenological researcher is to "accurately interpret lived experiences. . . In fact, the very worth of a phenomenological portrayal of reality must be judged in terms of how validly the research

represents the experiences of those who live the reality" (Swanson-Kauffman & Schonwald, 1988, p. 98).

Existential Phenomenology

Martin Heidegger (1889-1976) is credited with combining Husserl's phenomenology with the philosophy of existence. Existential phenomenology identifies itself with the justification of being-in-the-world. For Heidegger (1981/1993) being-in-the world means to "take into care beings as a whole" (p. xii). That is, one must be concerned with the whole, and not just a part of the whole. Heidegger believed that persons were to be studied in their totality, within their context. Existential phenomenologists are concerned with one's ability to think and to know as well as with their ability "to act, to plan, to use language, to evaluate, and perhaps most important of all, to ask who he is and what he ought to do" (Solomon, 1980, p.29). The existential phenomenologist shifts the "emphasis away from Husserl's question, "What is Knowledge?" to the very different question, "What is it to be a person?" (Solomon, 1980, p.29).

The present study sought a description of what it meant to be a person who lived in a family with a chronically ill sibling. Knowledge regarding long-term impact of a child's chronic illness on the well siblings is very limited. Thus, it was proposed that existential-phenomenological methods would offer a means of gaining an understanding of this

common experience. A description of the essential procedures defining phenomenology will be presented in Chapter III.

Relevance to Nursing

Understanding the lived experience of growing up with a chronically ill child is relevant for nursing since nursing is concerned with promoting health and its maintenance. The diagnosis of a child with a chronic illness affects the entire family. It is nursing's responsibility to understand the meaning of this impact on each member of the family. With this understanding, nursing interventions can be valuable and effective in promoting and maintaining the health and positive outcomes for each member in the family.

Participants

Participants in this study were adults who met the following criteria: 1) grew up in families with a child diagnosed with IDDM, and had no chronic illness of their own, 2) had not lived with their family of origin for at least one year, 3) were not presently living with the chronically ill sibling, and 4) verified that the chronically ill sibling was still living.

Summary

This study was designed to elicit an understanding of the experience of growing up with a chronically ill sibling from the first person perspective of the adult well sibling. It was hoped that this understanding would help ascertain if

siblings of chronically ill children experience long-term outcomes as a result of the phenomenon of growing up with a chronically ill sibling. A phenomenological method was chosen for this study because of its value in describing the lived experience of a person.

In the next chapter the literature concerning the impact a child's chronic illness has on the well siblings will be reviewed. This review will be followed by a discussion of the issues or concepts that may influence a person's perception of the stressors of having grown up with a chronically ill sibling, and some internal and external resources that may influence long-term impact.

CHAPTER II

LITERATURE REVIEW

The purpose of this study was to describe, from the adult's perspective, the experience of having grown up with a chronically ill sibling. The need for this study was determined following a review of the literature on the topic and from the experiences of the researcher.

In this chapter, extant literature will be reviewed. Special attention is given to the literature concerning the impact a child's chronic illness has on the well sibling who is still living with the immediate family. This literature review provides the foundation for the current research on adult siblings who grew up in a family with a chronically ill child but who are no longer living with that ill sibling. This review includes a discussion of the issues or concepts that may influence a person's perception of the situation of having grown up with a chronically ill sibling, as well as some internal and external resources that may influence long-term impact.

A review of the literature revealed a paucity of research concerning the adult sibling's perspective of having lived in a family with a chronically ill child. Therefore, studies of children were reviewed with respect to the impact a child's chronic illness has on a well sibling, still living with the immediate family. Research articles from the nursing, sociology, and psychology literature

spanning a period from 1977-1995 were reviewed. This time period was chosen because literature on chronic illness before this period concentrated on the ill child and his/her parents, with little emphasis on the rest of the family (Davis, 1975; Ferrari, 1983; Madan-Swain, Sexon, Brown, & Ragab, 1993). In fact, researchers have recognized siblings as the group who are often overlooked (Chesler, Allswede, & Barbarin, 1992). The literature reviewed was evaluated to determine: 1) source of information, 2) methodology, 3) major findings, and 4) issues influencing long-term outcomes.

Source of Information

A number of studies reported findings on the well siblings based on interpretations of observational or self-report data on children provided by parents (Breslau, 1982; Davies, 1993; King, 1981; Lavigne & Ryan, 1979; Marcenko & Smith, 1992). Many researchers are beginning to believe that information obtained directly from siblings about their experiences is more reliable than when such information is obtained from parents, teachers or health providers. For example, Lewis, Siegel and Lewis (1984) suggested in their development of the Feel Bad Scale that there are "strains in childhood that may not be appreciated as such by adults (e.g., having nothing to do, not spending enough time with parents)" (p.121). The importance of using the child as a source of information was seen in studies that reported

conflicting information between the child and the parent. For example, Menke (1987) found that school-aged children identified more concerns about themselves than the parents did and tended to see themselves changing less than their parents had observed. Ryan (1988) observed that children's perceptions about the sources of stress differed dramatically from adults' inferences. For example, it may be difficult for adults to imagine having nothing to do or being pressured to try something new as a major source of stress. Finally Walker (1988) found that there was a 44% disagreement between what the parents thought about how their children would cope and what the children revealed as their coping strategies.

The studies reviewed were limited in regard to the age groups studied since most studies used school-aged children. Studies to determine what effects a child's chronic illness has on well siblings who are preschoolers, adolescents and adults are lacking. Five of the articles reviewed used the adult sibling as a source of information. Gogan, Koocher, Foster, & O'Malley (1977) conducted a retrospective qualitative study on well siblings of children who had survived cancer. The interviews consisted of both forced-choice and open-ended questions. No information was given on how the data was analyzed. The sample consisted of thirteen well siblings, ranging in age from 8 to 28 who were 3 months to 17 years of age at the time of sibling's

diagnosis. There was an average of 13.5 years between initial diagnosis and time of interview. Many of the well siblings noted that the illness was seldom talked about in the family, but revealed feelings of intensified rivalry and jealousy. The authors found that because of a lack of communication between parents and children, some of the well siblings harbored guilt feelings for many years. The limitations of this study include a sample consisting of children and adults, and siblings of children suffering from a variety of forms of cancer.

Using a semi-structured interview adapted from another study (Knafl, Gallo, Zoeller, Breitmayer, & Ayres, 1993), Gerace et al. (1993) interviewed 14 adult siblings of schizophrenia patients to explore how they may have been influenced by the mental illness of their sibling. Questions were asked to elicit the subject's perspective on the sibling's mental illness on self, within the family system, and on the subject's perceived role in illness management. As adults, some were experiencing guilt about wanting to get away as well as "unreasonable" feelings of responsibility and powerlessness. Many subjects spoke of the losses of the ill sibling - lost potential, appearance, relationships, and life opportunities. In some cases, the siblings spoke of recognizing the illness before the parents did. A possible limitation of this study is that it is not clear how many of the subjects were living with the ill

sibling at the time of diagnosis. It is wondered if the impact of a sibling's illness differs if the diagnosis occurs while they are still living together with the immediate family.

Using existing data from the above study, Main et el. (1993) studied subjective descriptions of the siblings' experience of information sharing as it occurred presently, and while growing up with a schizophrenic brother or sister. Data was analyzed to identify common themes and relationships. They found that in families where denial and information withholding prevailed, children grew up feeling embarrassed about their sibling's illness and withheld information concerning their ill sibling's illness from others. Even as adults, because of the stigma of mental illness, some of these individuals withheld information from others concerning their sibling's illness. Only after establishing a trusting relationship with another person did these individuals reveal information about their sibling's mental illness. The participants in this study also expressed that they had to take the initiative to gather information for themselves and their family's benefit.

To determine the impact schizophrenia has on siblings, Lively, Friedrich, and Buckwalter (1995) interviewed 30 adults who had a sibling diagnosed with schizophrenia. Participants responded orally to the Impact on Relationships, Roles and Health scale, a questionnaire

partly developed by the investigators. Responses to the questionnaires were audiotaped, transcribed verbatim, and analyzed by means of content analysis to generate theme categories. Authors found that growing up with an ill sibling with schizophrenia created conflict and distancing in all family relationships. The relationship most affected was the one with the ill sibling. Siblings expressed a distancing in the relationship, as well as sadness and grief over the change in personality of the ill sibling. Anger and frustration also were expressed over the unfairness of life. Relationships with parents were also strongly affected. Well siblings reported that the ill sibling was the central focus of the family, depriving other members of time and attention. Well siblings also reported that the illness affected their leisure and pleasurable times, and provoked a personal fear of mental illness.

Lively, Friedrich, and Buckwalter (1995) reported that well siblings, as adults, had a continued feeling of conflict. This conflict resulted from the tension they felt by being pulled between giving attention to the ill person and to their own spouse. One limitation noted in this study is that the participants included those who had lived in the same household as the ill sibling and those who had not lived with the ill siblings.

Finally, Martinson and Campos (1991) using a semi-structured questionnaire interviewed 21 siblings of children

who had died 7 to 9 years earlier to determine the impact of the loss of a sibling on one's life and on relationship with the family. This study was a longitudinal follow-up at 7-9 years following the initial interview of adolescents whose siblings died at home from cancer during childhood. At the time of the second interview, the surviving siblings were between 17-28 years old. Interviews were audiotaped, transcribed and coded using a qualitative software program for analysis, called Ethnograph. Sixteen percent of these young adults expressed that the death of their sibling still had a negative impact on them. Negative impact included a dissatisfaction with the relationship with the dying sibling that persisted years later, avoidance of any discussion in the family concerning the sibling's death for fear of evoking emotional pain in their parents, and feelings of resentment concerning special treatment of the ill sibling. The authors of this study believe that it is possible that the relatively small percentage of adolescents reporting a negative impact from the loss of a sibling may be attributed to the reluctance of those with negative feelings to be interviewed. A limitation of this study was that the participants were interviewed in their homes, sometimes in the presence of parents or jointly with other siblings. Responses may have been different if all interviews were conducted in private.

Methodology

The studies reviewed used quantitative methods, qualitative methods, or some combination of the two. Many different objective tests were used in the quantitative studies. Two examples of these include the Louisville Behavior Checklist (LBCL) and the Piers-Harris Children's Self Concept Scale. The LBCL used by Lavigne and Ryan (1979) is concerned primarily with behaviors that reflect adjustment problems. The LBCL is completed by a parent about his/her child. It was developed and standardized for a broad age range of children. Also there was no comment as to the reliability and validity of this instrument.

The Piers-Harris Children's Self-Concept Scale used by Ferrari (1987) and Cairns, Clark, Smith, & Lansky (1979) assesses children's perception of themselves. There was no mention of reliability and validity of this instrument by either author.

A number of researchers used only a single instrument in their study, while others used more than one. It is unlikely that the measurement of a single variable will give the necessary information needed to understand the dynamics of a family with a chronically ill child. When researching the effects a child's illness has on well siblings, the researcher must be aware that many times the instruments used were developed for other populations. Kazak and Nachman (1991) suggest that "in attempts to measure family

functioning with paper-and-pencil measures, it must be remembered that a good score on a particular outcome measure is limited to how good the measure is, psychometrically" (p. 476). Designs that require a respondent to make forced choices eliminate the complexity and variety of meaning available for interpretation. They are left out deliberately so that unambiguous data can be developed (Polkinghorne, 1983). According to Polkinghorne (1983) "a model of science which cannot include ambiguous and interpretable statements gains precision in analysis, but it loses the character of the experienced world" (p.238).

Control groups were lacking in a number of the quantitative studies reviewed. Feeman and Hagen (1990) used a control group, although the comparison data came from a prior study. The control group used by Breslau (1982) had a much higher median income than the disabled group. This difference in income could lead to serious misinterpretations, since Taylor (1980) found a direct relationship between lower income and the negative effects upon the well children. The use of well structured control groups in quantitative studies must be more consistent in order to give support to the findings. Without control groups it is difficult to determine if the results obtained are from the unique experience of having a chronically ill sibling.

Although the majority of qualitative studies reviewed relied on semi-structured interview methods, one researcher used puppets and drawings (Walker, 1988) and another used pictorial stimuli (Spitzer, 1992). The use of a semi-structured interview may influence the findings in a study. This occurs when participants feel obligated to answer questions posed by the researcher. None of the studies reviewed used phenomenology as its philosophical and methodological base. It is this approach, though, that will give us a first-person description of the meaning of an experience. The use of an unstructured interview, using open-ended questions to have the participant clarify or elaborate, will allow the participants to describe their perceptions of the experience.

Major Findings

The major findings were organized as follows: 1) stressors reported by the well siblings; 2) studies reporting negative outcomes for siblings of chronically ill children; and 3) studies reporting positive outcomes for the well siblings.

Stressors of well siblings

The specific stressors reported by the well siblings of chronically ill children were compiled and are presented in Table 1. Most researchers acknowledge that stressors are an inevitable condition of life, which by themselves, do not predict outcomes or adaptation. Although people may

Table 1 Stressors of Well Siblings

Stressor	Study Reporting Stressor
Lack of parental attention	Gallo et al., 1991; Iles, 1979; Kramer, 1984; Taylor, 1980
More responsibilities	Gallo et al.,1991; Iles, 1979; Kramer, 1984; Taylor, 1980
Lack of information regarding ill child	Iles, 1979; Kramer, 1984; Taylor, 1980
Changes in sibling relationship	Iles, 1979; Martinson & Campos, 1991
Altered peer group/Peer teasing	Iles, 1979/Faux, 1991
Alteration in physical appearance of ill child	Iles, 1979; Kramer, 1984; Menke, 1987
Staying home by themselves	Iles, 1979
Fear of own health	Cairns et al.,1979; Menke, 1987;Taylor, 1980; Martinson et al., 1990
Social isolation	Cairns et al., 1979; Kramer,1984; Taylor,1980; Martinson&Campos,1991
Lack of involvement in child's care	Taylor, 1980
Deprived of recreational experiences/ other material items	Gallo et al., 1991; Taylor, 1980
Lack of touch and physical closeness	Taylor, 1980
Fear of prognosis of ill child	Gallo et al., 1991; Taylor, 1980; Walker, 1988
Emotional deprivation	Kramer, 1984
Decreased parental tolerance	Kramer, 1984
Witnessing ill child's anxiety and pain	Kramer, 1984; Martinson & Campos, 1991
Adjusting to changes in usual family routines	Kramer, 1984; Menke, 1987; Walker, 1988; Martinson & Campos, 1991
Concerns about parents/ill child	Menke, 1987/Faux, 1991; Gallo, et al., 1991; McCarthy & Gallo, 1992; Menke, 1987
Embarrassment when ill child is teased	Faux, 1991; Menke, 1987
Decrease family finances	Martinson & Campos, 1991
Differential treatment from parents	Chesler et al., 1991

experience similar stressors there are individual differences in the degree and kind of reaction to them. People differ in their sensitivity and vulnerability to certain types of events, as well as in their interpretations and reactions (Lazarus & Folkman, 1984). Despite similar stressors, both positive and negative outcomes have been reported for siblings of chronically ill children. These negative and positive outcomes are summarized briefly as follows:

Negative outcomes

Negative outcomes for siblings of chronically ill children were reported by a number of authors. Lavigne and Ryan (1979) reported well siblings as being more withdrawn, having increased adjustment problems, increased behavioral problems, and increased irritability. Siblings of children with cancer were reported by Cairns et al., (1979) as having increased anxiety, fear of their own death, social isolation, and negative body image. The well children saw the mother as overprotective and overindulgent of the ill child. Other negative outcomes reported for well children included disruption of interpersonal relationships and routines (Iles, 1979, Lively et al., 1995), increased competition, anger, hostility, social withdrawal (Taylor, 1980), decreased school performance (Taylor, 1980, Lively et al., 1995), increased sibling rivalry (Taylor, 1980, Gallo, 1990), jealousy (Martinson, Colaizzo, Freeman, & Bossert,

Taylor, 1990), fear of their own death (Walker, 1988), and increased somatic complaints (Ferrari, 1984).

Ferrari (1987) examined the self-esteem of the well siblings of diabetic children. The sample consisted of 30 siblings of diabetic children and a control group of 30 siblings of well children. Each child was given the Piers-Harris Children's Self-Concept Scale to complete. Ferrari (1987) reported the well siblings as having decreased self-esteem as well as concerns regarding their intellectual and school status, personal happiness and life satisfaction. His explanation for this pattern of results was that "children interpret differential treatment by parents, particularly when a disabled child is present in the family, as an indication of lessened parental value on their development" (p. 146). Limitations of this study included the administering of one instrument only one time, the sample consisting only of school age children, and not including all of the well siblings in the family.

Gallo, Breitmayer, Knafl, and Zoeller (1992) studied 28 families of chronically ill children to determine the psychological adjustment of well siblings. Each parent individually completed the Child Behavior Checklist (CBCL) at two data collection sessions conducted 12 months apart. The CBCL assesses the behavior and social competencies of children ages 4 to 16. Although well siblings were found to have no more behavior problems than the normative sample,

the authors noted a deficit in social competence as rated by fathers and in social relationships as rated by mothers and fathers. Limitations in this study as noted by the authors included sibling adjustment only measured by parents, small sample size of various illnesses, and comparison with normative data rather than to a control group.

Positive outcomes

Many authors reported positive outcomes for siblings of chronically ill children. These included increased nurturing, cooperation, sensitivity (Taylor, 1980), compassion (Ferrari, 1984; Taylor, 1980), empathy, respect, (Iles, 1979), personal maturation, and family cohesion (Ferrari, 1984; Kramer, 1984).

Issues Influencing Long-Term Outcomes

The issues that may influence a person's perception of the stressors of having grown up with a chronically ill sibling, and some internal and external resources that may influence long-term outcomes for the well siblings, include the following: 1) age and/or developmental stage of well child at time of diagnosis, or gender of the well sibling, 2) caretaker role of well sibling, 3) communication within the family, 4) sibling relationships 5) social support, 6) self esteem of the well sibling, and 7) coping patterns of the well sibling.

Age, Developmental Stage, and Gender

There is some evidence to suggest that age, developmental stage, or gender of a child may be factors with regard to a child's ability to handle stress and thus influence the long-term outcomes for that child. Gallo et al., (1991) found that younger siblings tended to be more secretive about the child's illness than the older siblings. They believed this difference occurred because the younger child lacks an understanding of the causes of illness and frequently holds the ill child responsible for the illness, thereby needing to hide the chronic illness from others. Gallo, Breitmayer, Knafl, and Zoeller (1992) reported that "siblings younger than the ill child tended to display more behavior problems than siblings older than the ill child" (p. 25). Lavigne and Ryan's (1979) study on siblings of children with chronic illness showed that younger female siblings appeared to have more adjustment problems than younger male siblings. Older female siblings tended to have slightly fewer adjustment problems than older male siblings.

In direct contradiction to the above study, Breslau (1982) found that males younger than the disabled child, specifically those in close age-spacing, showed greater psychological impairment than those older. Females who were younger than the disabled child were better off than those who were older, and age-spacing was not significantly related to psychological functioning. Conflicting results

obtained in the above two studies could have occurred for a number of reasons. The most likely reason is that the studies involved different illness groups with durations of illness, prognosis and the age of the ill child when diagnosed.

Children who were very young (ages two and three) at the time their sibling was diagnosed with cancer were found by Kramer (1984) to express less jealousy and anger than those who were older at the time the ill child was diagnosed. Using children's self-report measures, Madan-Swain et al. (1993) found that older siblings of children with cancer perceived a decrease in family involvement. Their explanation was that older siblings may have been given greater responsibility for caring for younger siblings and for domestic activities at home while their sibling was ill. They concluded that having an ill sibling results in increased responsibility for older siblings and decreased participation in family activities which, in turn, results in less positive feelings regarding their family and the cancer experience. The three groups (siblings, patients, and controls) compared in this study consisted of 32, 19, and 10 children respectively. The control group of children were not matched for gender or family income with the siblings of the ill children and any differences could have resulted from not having a matched control group.

Finally, Ferrari (1987) designed a study to determine if the well sibling's self-concept was influenced by birth order, sex of the well sibling, or sex of the ill child. He found that younger siblings generally had lower self-concept scores when compared with older siblings. Male siblings of males with diabetes had the lowest overall self-concept scores.

Caretaker Role of Well Sibling

Well siblings who were in the caretaker role for the ill child were reported by some authors as having a more positive experience (Martinson & Campos, 1991; Martinson et al., 1990). For example Martinson and Campos (1991) interviewed persons from 17 - 28 years of age whose sibling had died 7 to 9 years earlier. They found that siblings who described even a small caretaker role were less likely to attribute negative effects to their sibling's death. Other researchers, though, believe that the caretaker role may have a negative impact on the well siblings. According to Chesler, Allswede and Barbarin (1992) the caretaker role "may prematurely cast siblings into a parental role and prevent the unique and separate development of their own identity" (p. 28). Gallo (1988) states that "the well sibling may view parental expectations for increased domestic and child care chores as an indication that the parents are not concerned with them as individuals but only as persons meeting the needs of others" (p. 32).

Communication Within the Family

Communication is defined by King (1981) as "the interchange of thoughts and opinions among individuals. . . the means whereby social interaction and learning takes place" (p. 62). King (1981) states that for communication to be effective it has to "take place in an atmosphere of mutual respect and desire for understanding" (p. 62). Encouraging communication between well children and their families is an important nursing intervention. When siblings are not kept informed they often fill in the gaps with misconceptions (Kramer, 1984; Sourkes, 1987). Taylor (1980) reported that the children who were given frequent and complete information about their sibling's illness expressed more positive outcomes from the experience. On the other hand "in an atmosphere of restricted communication, in which siblings function without full knowledge of the problem, they likely experience considerable, ongoing stress" (McKeever, 1983, p.213). According to Siemon (1984) "protecting siblings from information and excluding them from full participation in family problems increases loneliness and anxiety" (p. 301). Both Iles (1979) and Kramer (1984) reported that when well siblings were asked directly what would help them deal with the situation they expressed the desire to have more information about the disease and its treatment. Communication is often viewed as a key factor in resolving

stressors associated with chronic illness (Butcher, 1994).

Communication, though, can be very difficult for both the parent and the well siblings. According to Chesler and Barbarin (1987) "in some families a wall of silence separates members; so much privacy is maintained that family members have little sense of each other's anguish, despair, or pain. . . if pain or fear cannot be shared, love may not be shared either" (p.122). This wall of silence can easily develop in families who believe their love for one another compels them to protect each other from pain. This was clearly seen in a study done by Canam (1987) who, using a guided interview technique, interviewed fifty-seven parents of chronically ill children to determine how parents communicate within the family about feelings concerning their child's chronic illness. Interviews were taped, transcribed verbatim, and then analyzed for common categories and themes. She found that the majority of parents did not talk about their own feelings nor did they encourage their well child to talk about their own feelings. Reasons given for not talking to the well children included that (a) it did not occur to them to do so, and (b) they did not want to make the child feel worse. Parents believed they were protecting their well children from pain, thus leading to a lack of communication between family members. In this study, though, some of the parents were interviewed

together and responses may have been different if interviews had been conducted separately.

In families where open communication of feelings is not practiced, members may feel that their feelings or needs are less important than those of other family members. In their study of well siblings of children who were living with cancer and children who died of cancer, Martinson et al (1990) found that well siblings had feelings of jealously which often could not even be acknowledged until the ill sibling had recovered. They state that "in a family that has faced life-threatening illness, and in which the possibility of relapse remains, children can be expected to withhold expression of their own concerns as being somehow less important compared to the child with cancer" (p. 188). This suppression of their own needs may occur in childhood only to have them erupt later in early adulthood (Leonard, 1991).

Effective communication between the parent, the well siblings, and the ill child is necessary if all members of the family are going to adapt to a child's chronic illness (Canam, 1987). Chesler and Barbarin (1987) believe that "trusting and sharing feelings promote intimacy and cohesion that strengthen the family's ability to respond to the illness" (p.122). Open communication in families can help to create a growth experience out of an initial stressful situation. According to Younger (1991) "growth often

occurs in situations of novelty and stress, developmental transitions, threats to self, and loss of previously comfortable ways" (p.86) Growth creates individuals with the capacity to have and show compassion for fellow human beings.

Sibling Relationships

Sibling relationship, as defined by Powell and Ogle (1985), is an interaction that "provides two people with physical and emotional contact at critical stages throughout their lives" (p. 10). Sibling relationships can have a major impact on a child's development (Powell & Gallagher, 1993). Sibling relationships according to Furman & Buhrmester (1985) can be "close or distant, harmonious or conflicted, cooperative or competitive" (p. 448). It must be remembered, though, that sibling relationships are dynamic with varying degrees of love, hate, jealousy, competition, and companionship. Siblings often quarrel, but they often find themselves teaching and defending each other.

It is believed (Dunn & McGuire, 1992) that sibling relationships are linked to maternal differential treatment and that "the more differential the maternal behavior is shown, the more conflict and negative behavior the siblings show to each other" (p. 72). This is a very important consideration in families with a chronically ill child. Some well siblings may perceive physical care and/or concern

for the ill child as differential treatment, thus influencing the sibling relationship adversely. Such perceptions may result because of their sense of loss, jealousy, and concern (Chesler & Barbarin, 1987). This is clearly indicated in the study done by Bendor (1990) on children with cancer who found that the well siblings perceived their parents as consistently unfair to them and overly indulgent of the sick child. Well siblings considered the parents' different attitudes towards fighting between siblings as the most blatant example of unfairness. The sick child was often permitted to hit his/her healthy siblings, who were never allowed to hit back.

Often siblings identify with one another, believing that they will experience the same outcomes or fate (Chesler & Barbarin, 1987). This perception is extremely important when one sibling becomes chronically ill. A number of researchers have documented the fears of the well siblings concerning their own health (Cairns et al.,1979; Martinson et al., 1990, Menke, 1987; Taylor, 1980).

A more complete understanding of the sibling subsystem may be necessary to help explain the negative or positive experience a child's chronic illness has on the well siblings. The influence of sibling relationships is an under-researched experience in the extant literature on the long-term impact a child's chronic illness may have on both the ill child and/or the well sibling.

Social Support

Social support has to do with many everyday circumstances: sharing tasks and feelings, exchanging information, and affection. Vaux (1988) defines social support as a "complex transactional process involving an active interplay between a focal person and his or her support network" (p.30). He differentiates social support into three components: support network resources, supportive behavior, and subjective appraisals of support. Support network is that group of individuals to whom a person routinely turns for assistance in managing problems or achieving goals. Supportive behaviors are the specific efforts that are made to help another: emotional, feedback, advice/guidance, practical, financial/material, and socializing. Finally support appraisals are the "subjective, evaluative assessments of a person's supportive relationships and the supportive behavior that occurs within them" (p.29).

In adults who are under stress social support has been found to reduce the risk of developing psychopathology (Jenkins, 1992). Social support has also been found to be a significant predictor of adjustment to chronic illness (White, Richter & Fry, 1992). Social support for well siblings, which is provided by parents, teachers, siblings, relatives and peers, may act as a buffer in preventing negative long term outcomes of living with an ill sibling.

Madan-Swain et al. (1993) found that the more siblings in the family, the better the adjustment reported by all siblings. They believe that in families where there are many siblings, different sibling subsystems may emerge providing support for well siblings during times of parental over-involvement with the ill child. Having more siblings than just the ill sibling may also be important in regards to the concept of reliable alliance. According to Vaux (1988) reliable alliance is "provided primarily by kin (especially siblings), who may be called upon for continued assistance even in the absence of mutual affection. In the absence of reliable alliance, the individual may feel vulnerable and abandoned" (p. 5). One wonders if in families with a chronically ill child whether the number of siblings in the family become important in relation to reliable alliance? Studies linking number of siblings in a family with a chronically ill child to long-term outcomes for the well sibling are lacking.

Self-esteem of the well sibling

Rosenberg (1979) distinguishes between self-concept and self-esteem. Self-concept is the "totality of the individual's thoughts and feelings having reference to himself as an object" (p. 7). Self-esteem is "self acceptance, self-respect, and feelings of self-worth" (p. 31). Rosenberg (1979) believes that self concept is largely shaped by the responses of others and states that "other

people's judgements of us matter enormously; indeed, there is probably no more critical and significant source of information about ourselves than other people's views of us. . . the very sense of self arises through the process of adopting the attitudes of others toward the self" (p. 64).

According to Reasoner (1983) "in a warm and empathetic environment, children are likely to develop positive feelings of personal worth and to learn self-acceptance. In a home environment lacking in empathy or communication, children are apt to develop feelings of insignificance by being deprived of their basic source of positive feedback" (p. 52). Characteristics of persons with high self-esteem include being candid, willing to take risks, satisfied with life, having a respect for themselves, liking themselves, and are self-accepting. Characteristics of persons with low self-esteem include being more depressed, less happy, having a higher negative affective state, having increased anxiety, and having more somatic complaints (Rosenberg, 1979).

What happens to the self-esteem of a child who lives in a loving home, where parents must focus their attention and energy upon the immediate demands of a chronically ill child, thus having less energy for meeting the emotional needs of the well siblings? Out of necessity the needs or desires of the well siblings may often be neglected.

The studies on the self-esteem of siblings of chronically ill children have produced conflicting results.

For example, Ferrari (1987) reported that well siblings have a decreased self-esteem as well as concerns about their intellectual and school status, personal happiness and life satisfaction. He explained this came about because "children interpret differential treatment by parents, particularly when a disabled child is present in the family, as an indication of lessened parental value on their development" (p. 146).

In contrast to the results of this study, Gayton et al. (1977) reported that siblings of children with cystic fibrosis had a higher self-concept score than data reported for normal children. The instruments in this study measured self-concept, personality, and personality functioning. The authors noted that the instruments used did not measure the possible psychosocial consequences associated with having a sibling with cystic fibrosis. The limitations to this study included a small sample (n=31), testing children only once, and not controlling for length of illness.

The lack of longitudinal studies precludes drawing any conclusions concerning the self-esteem of the well siblings of chronically ill children. It is unknown what the long term impact of living in a family with a chronically ill sibling has on one's self- esteem.

Coping Patterns of the Well Sibling

Coping, as defined by Lazarus and Folkman (1984) is the "constantly changing cognitive and behavioral efforts to

manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Lazarus and Folkman distinguish between problem-focused coping and emotion-focused coping. Problem-focused is directed at managing or altering the problem causing the distress, usually occurring when such conditions are appraised as amenable to change. Emotion-focused coping is directed at regulating emotional response to some problem. Emotion-focused coping usually occurs when there has been an appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions. Some examples of emotion-focused coping include avoiding, minimization, distancing, selective attention, positive comparisons, and wresting positive value from negative events.

Many times siblings of chronically ill children are not in control of the events causing their stress; therefore, emotion-focused coping is often observed in these children (Kramer, 1984; Taylor, 1980; Walker, 1988). Madan-Swain et al. (1993) found that siblings of children with brain and other tumors engaged in greater frequencies of wishful thinking as a coping adaptation than siblings of acute lymphocytic leukemia. They believed this occurred because tumor patients required fewer clinic visits and, therefore, siblings had fewer opportunities to access information and support from the medical team. As stated before, the

results of this study were based on a small sample size and unequal groups.

Using Lazarus and Folkman as her theoretical framework, Spitzer (1992) found that hemophilic children use both emotion-focused and problem-focused coping strategies. She found coping to be context bound and related to the extent to which an event was perceived as being amenable to change. Her results showed that "in the context in which the children could change some aspects of the situation, they used predominantly problem-solving forms of coping (applying a bandage). However, in the areas which were not amenable to change, children used predominantly emotional regulating forms of coping" (p. 165) (distraction, avoidance, minimizing, self talk).

The relationship between locus of control and preoperative coping in children was studied by LaMontagne (1987). In this work, LaMontagne (1987) found that children's locus of control orientation may be an important variable in how they cope with the stressors of surgery. She found that subjects with internal locus of control were more likely to adopt active coping behaviors whereas subjects with an external orientation were more likely to adopt avoidant strategies.

The above two studies are quite significant for siblings of chronically ill children. Control of a situation is an important concept for Lazarus and Folkman

(1984). According to them "one's belief in one's ability to control an event influences how that event is appraised and, through appraisal, subsequent coping activity" (p. 76). Although siblings of a chronically ill child are directly and immediately affected at the time of the child's diagnosis, many times the well siblings are not in control of the events causing stress. They are often powerless in regard to the many changes that occur or the decisions that are made by their parents. For example, parents can seek and are provided with information concerning the illness although, in most cases, the well siblings are dependent on their parents to provide this information to them (Davies, 1993). Often the parents' solutions for handling their own stress will mean added stress for the well sibling (e.g., parents deciding to be with the ill child in the hospital, leaving the siblings alone with other family members or friends; relocation of family home to be near to medical facilities, etc.). It is important to remember, though, that all the research done on coping by Lazarus and Folkman (1984) used adult subjects and one must wonder if their results can be applied to children.

Ryan-Wenger (1992) developed a taxonomy of coping strategies that elementary school-aged children use in dealing with stressful events. Ryan's taxonomy of children's coping strategies is "non-hierarchical in that the categories are not more and more inclusive, but are

mutually exclusive... one category is not considered more desirable or more important than another" (p. 259). Her study revealed the following 15 categories of strategies used by children: aggressive activities, behavioral avoidance, behavioral distraction, cognitive avoidance, cognitive distraction, cognitive problem-solving, cognitive restructuring, emotional expression, endurance, information seeking, isolating activities, self-controlling activities, social support, spiritual support and stressor modification.

Similar coping strategies were described by Walker (1988) in her study concerning siblings of oncology patients. Three sources of stress for siblings were identified as loss, fear of death, and change. In coping with these stresses, the three domains of cognitive coping strategies identified were intrapsychic (wishful thinking, denial), interpersonal (talking to others), and intellectual (school project, learning). The domains for behavioral coping strategies were identified as self-focusing (somatization), distraction (playing alone, eating), and exclusion (temporary escape). This study is important because after the specific coping strategies of siblings of chronically ill children are identified it can be determined which coping strategies contribute to more positive adjustment.

Finally Ryan-Wenger (1990) studied 8-12 year old, white children to determine the type, frequency, and effectiveness

of children's stress-coping strategies. She concluded that "the perceived degree of coping effectiveness was not significantly different among the age groups, which supports the notion that children of all ages are able to cope reasonably well with stressors" (p. 349). Since this study was done on school-aged children who may not have been experiencing unusual stressors, this conclusion may not be generalizable to children who have a serious illness or children who have a sibling with a chronic illness.

Summary

The literature review clearly identifies the stresses associated with having a chronically ill sibling and the well child's perception of these experiences as having a significant short-term positive and/or negative impact on them. Also identified were issues that may influence a person's perception of the stressors involved in growing up with a chronically ill sibling. It also identified internal and external resources that may influence long-term impact. What is lacking in the extant literature is a description of the experience of growing up with a chronically ill child through the perception of the well sibling who is now an adult. This adult view appears to be an important missing link in understanding the long-term impact a child's chronic illness has on the well siblings.

There are no studies that interviewed adults who grew up with a chronically ill sibling. Such studies would

increase an understanding of this experience. This understanding may provide nurses with essential information for giving wholistic care to families having a child with a chronic illness. It is believed that in order to understand the phenomenon of having a chronically ill sibling, the focus of research needs to be on describing what the experience means to the individual who grew up with a chronically ill sibling. Thus, the current study, using phenomenology as its philosophical and methodological base, was conducted on adults to further our understanding of the phenomenon of growing up with a chronically ill sibling.

CHAPTER III

METHODOLOGY

This chapter includes the following: (1) an overview of existential-phenomenology, (2) a discussion of the criteria for participation in the study, (3) ethical concerns of this study, (4) a description of the essential procedures in the phenomenological method to be used in this study, and (5) a discussion of the reliability and validity within the context of these procedures.

Existential Phenomenology

In this study, a methodology deriving from an existential-phenomenological approach to studying human experience was employed to obtain a description of the experience of having grown up with a chronically ill sibling. According to Thompson, Locander, and Pollio (1989) "existential-phenomenology is a paradigm that blends the philosophy of existentialism with the methods of phenomenology. The result is a contextually based, holistic psychology that views human beings in non-dualistic terms and seeks to attain a first-person description of experience" (p. 133).

Two of the assumptions of existential-phenomenology are pattern and figure/ground. A pattern is a perceived whole, emerging from some context. Edgar Rubin (1886-1951) is credited with emphasizing the distinction between the figure- "the substantial appearance of objects" and the

ground- "the general homogeneous environment in which the object exists" (Wertheimer, Koffka, & Kohler, 1991, p.504). He believed that perceptual experience is selective; thus, stimuli perceived with greater clarity define the figure of some experience, with the remainder of the event providing the ground. The figure/ground structure of experience clearly implies that what is figural for one person may be ground for another; thus, different settings may determine different experiences for individuals experiencing the same physical event (Thompson, Locander, & Pollio, 1989). Although the phenomenologist expects to find diversity in human experience, he or she also expects through this diversity to extract the essential themes for the participants concerning the phenomenon of intent.

The circumstances of growing up with a chronically ill sibling can be very similar for all well siblings, the experience, however, will differ according to one's perception of the situation. Previous research suggests conditions that may influence this perception. These include the degree of communication in the family (Kramer, 1984; Taylor, 1980), sibling relationships (Chesler & Barbarin, 1987), social support (Madan-Swain et al., 1993), and individual coping patterns (Madan-Swain et al., 1993). No study, though, could be found that was specially designed to have adults describe their experience of growing up with a chronically ill sibling. The phenomenological method used

in this study provided adults, who grew up with a chronically ill child, the opportunity to describe their perceptions of the experience. This description of the experience was important to facilitate the recognition of the essential themes of the phenomenon, and thus, help others understand the meaning of growing up with a chronically ill sibling.

Participants

This study included participants who met the following criteria:

1) Grew up with a sibling having IDDM.
2) Did not have a chronic illness of their own when growing up.
3) Did not have a personal or family history of a major mental illness.
4) Had not lived with their chronically ill sibling or family of origin for at least one year prior to the study.
5) Were willing and able to discuss the experience.
6) Were older than 21 years of age.
7) Their sibling with IDDM was still living.

Participants who were not living with the chronically ill sibling and their family of origin were sought for two reasons: (1) it was believed that these individuals would be more likely to discuss the experience of growing up with a chronically ill sibling, and (2) they would have had time to

reflect on the experience, and by reflecting on the experience know what it is they have lived through (Oiler, 1982). Participants were recruited by placing an ad in the newspaper, by contacting the American Diabetic Society, and by word of mouth. Participants who met the criteria listed above were interviewed until the material presented no new contribution to the emerging description of the structure of the experience; that is, when no new themes could be identified.

The following demographic data were collected from each participant: (1) gender, (2) age, (3) marital status, (4) education, (5) occupation, (6) age of ill child at time of diagnosis, (7) age of well sibling at time of diagnosis, and (8) length of time spent living with chronically ill sibling.

Ethical Concerns

Prior to beginning this study, approval was obtained from the College of Nursing human subjects review committee and the University of Tennessee Institutional Review Board. Before being interviewed each participant was informed of the purpose of the study, and written and oral informed consents were obtained. Participants were informed that they were under no obligation to take part in the study and that they could withdraw at any time without penalty. To assure anonymity all participants were given a pseudonym by the researcher, which was used to identify their interviews.

This pseudonym will be used in the material quoted concerning the results of this study. All interviews were audiotaped and then transcribed verbatim. Audiotapes were erased at the end of the study. Those members of the interpretative group participating in the analysis of data were asked to sign confidentiality statements.

An ethical concern was that participants might experience a variety of emotions during the interview as a result of sharing childhood experiences. The researcher has Master's degrees in both nursing and in counseling and was qualified to provide immediate intervention, if needed. Proper referrals for additional care were made as appropriate.

Essential Procedures of the Phenomenological Method

The essential procedures of the phenomenological method that were followed in this study and are described below include: 1) Bracketing, 2) Intuiting, 3) Phenomenological Analysis, and 4) Describing. Although these components will be described separately, it must be remembered that they are interdependent, influencing each other throughout the investigation.

Bracketing

The phenomenological method is intended to be as free from prejudgments and personal beliefs as possible. The ideal, but not the reality, is for the elaboration of a purely descriptive philosophy in which there are no initial

assumptions (Farber, 1966). Husserl believed it was possible to free oneself as far as possible of prejudgments and biases, and to become aware of one's perceptions, through the technique of bracketing. Bracketing is an "attempt to bridge the gap between the researcher's own experience of the phenomenon studied and the reality that exists outside of the investigator's personal world" (Swanson-Kauffman & Schonwald, 1988, p. 98-99). According to Pollio, Henley and Thompson (1995) "bracketing is a suspension of theoretical beliefs, preconceptions and presuppositions" (p.70). Bracketing assists the researcher in addressing preconceptions about a phenomenon fully and openly. The researcher brackets by stating assumptions held concerning the phenomenon being studied, essentially permitting the beliefs of the researcher concerning the phenomena of interest to be made known. Once known, assumptions and beliefs must be held in abeyance, allowing other views to come into perspective. Bracketing does not "eliminate perspective, it brings it into view" (Oiler, 1982, p.180). Thus, bracketing permits the researcher to understand how beliefs and values influence perceptions.

Although complete bracketing is impossible (Pollio, Henley, & Thompson, 1995), certain procedures can be implemented to strive towards the ideal. These procedures include 1) rendering any interpretation in the words of the participants, 2) conducting some of the interpretation of

research interviews within a group setting, and 3) use of a bracketing interview (Pollio, Henley, & Thompson, 1995). Before data collection was initiated in this study a bracketing interview of the researcher was done. The bracketing interview was a formal interview on the topic of study. This interview allowed the researcher to make her assumptions and biases regarding her perspectives on the experience of growing up with a chronically ill sibling known. The bracketing interview was audiotaped and transcribed verbatim. The transcribed interview was read and interpreted within the context of the Phenomenology Group at the University of Tennessee. This group consists of individuals who are familiar with existential-phenomenological research. The multiple perspectives of group members assisted the researcher in bracketing her biases throughout the investigative process (Thompson et al., 1989). The group perspective also enabled the researcher not to influence the data with her biases either during the interview or during the interpretive phases. Through the bracketing interview, the researcher learned that she believed parents of chronically ill children would have a tendency to treat these children in a special manner.

Intuiting

Intuiting is the researcher's ability to become involved, to become empathic to the informants' reality without losing objectivity. According to Oiler (1982) it is

"looking at the experience with wide open eyes, with knowledge, facts, theories held at bay; looking at the experience with astonishment" (p.180). Intuiting is accomplished through a phenomenological interview. The goal of the interview is to attain a first-person description of the meaning of the phenomenon of interest. According to Polkinghorne (1983) "the face-to-face encounter provides the richest data source for the human science researcher seeking to understand human structures of experience" (p. 267). During the interview the researcher adopts a posture of naivete in regards to the phenomenon, for in reality the researcher knows nothing of the topic as experienced by the participant (Thompson et al., 1989). According to Pollio, Henley, & Thompson (1995) "the interview is a human event that yields interpretable data if approached properly. Such data reflect the participant's perspective on his/her experiences as they emerge in the context of an interview" (p.45).

In the present study the goal of the phenomenological interview was to attain a first-person description of the lived experience of growing up with a chronically ill sibling. The interview was unstructured, used open-ended questions, and began by requesting the participant to: "Tell me what it was like to have a chronically ill sibling." Further questions in the interview were limited to areas of clarification or elaboration. Except for the initial

question, all questions flowed from the dialogue. Participants were interviewed individually for approximately one hour at a location of their choice.

Phenomenological Analysis

The analysis phase, according to Munhall and Boyd (1993), "is a matter of identifying those elements of a phenomenon that entail a relation which, if omitted, would annihilate the phenomenon" (p. 111). Analysis involves comparing and contrasting descriptions produced by a number of participants to identify recurring elements. It allows "the identification of the ingredients of the phenomenon and the way the ingredients relate to each other" (Oiler, 1982, p.180). Using the pattern metaphor the "experience is seen as a pattern that emerges from a context" (Thompson et al., 1989).

Analysis of participants' experiences in the current study was done within the context of a hermeneutical approach. With this approach, no passages in the protocol are taken out of context, but rather are read in light of the whole (Reeder, 1988). According to Thompson et al.(1989) "interpretation is a continuous back and forth process of relating parts to the whole" (p.140). For the "parts of the text are not a mere mechanical collection; they are a complex which hangs together in a unity which is the meaning of the text" (Polkinghorne, 1983, p.226). An understanding of a given participant's protocol is obtained

through a "movement from the first prejudgmental notion of the meaning of the whole, in which the parts are understood, to a change in the sense of the meaning of the whole because of the confrontation with the detailed parts of the text" (Polkinghorne, 1983, p.227). This movement from part to whole increases the depth of understanding (Polkinghorne, 1983).

Some of the research protocols were read within the Phenomenology Group. The purpose of the group was "to orient both the researcher and the interpretive group to the nature of the data, and to alleviate the difficulties of beginning to organize and interpret qualitative data" (Pollio, Henley, & Thompson, 1995, p.74). This approach continued to help focus the researcher on her assumptions, thus allowing for the attainment of a thematic description of the experience of the participants. Analysis of individual protocols was done through providing the evidence within the transcript, using the respondent's own words in order to support a given interpretation. At no time was a part of the protocol taken out of its overall context. Participant protocols were then related to each other to identify common patterns or global themes (Thompson et al., 1989). Patterns and themes emerge by investigating the phenomenon from various participants (Wertz, 1986). The researcher looked for common patterns in the experience of growing up with a chronically ill sibling.

Describing

Describing is a classification, or grouping, of the phenomena, a guide to an understanding of the phenomenon. Because the researcher cannot report all data in their totality, results of a phenomenology study are organized according to themes. The goal of phenomenology is to describe an experience, not to interpret or explain the data (Strauss & Corbin, 1990). Phenomenological description brings "to evident consciousness the essence of that which is experienced. . . it is an account of all the pertinent facts; it cannot be an account of all the facts, because the facts are infinite in number" (Farber, 1966, p.44-45). It is a description of what has been seen and heard by the researcher. According to Oiler (1982) "a successful description directs the listener to his own experience of the phenomenon" (p.180). The purpose of this study was to describe the experience of growing up with a chronically ill sibling from the perspective of those who have experienced this phenomenon.

Validity and Reliability

Validity and reliability must be considered when doing qualitative research. Validity is measured both externally and internally. It is suggested by Sandelowski (1986) that external validity in qualitative research be evaluated by its fittingness. Fittingness is obtained when "the findings

are well-grounded in the life experiences studied and reflect their typical and atypical elements" (p.32).

Fittingness in the proposed study was obtained by using the participant's own words to support any interpretations that were made by the research group. Themes were validated through the words of the participants. This is necessary to provide an experience-near description of the phenomenon. One must always be cautious about adding information that is not directly evident in the protocol. The phenomenological investigator is not interested in explanations or theories, but in the experience of participants (Wertz, 1986). It is important to remember, though, that validity "does not preclude the existence of alternative interpretations nor does it require the reader to believe that the present interpretation is the only or even the best one" (Pollio, Henley, Thompson, 1995, p.79). The question that must be answered if the study is to be considered as valid is as follows: "Is there convincing evidence for believing that the thematic description affords insight into the experiential world of the participants?" (Pollio, Henley, Thompson, 1995, p.79).

Internal validity in qualitative research is obtained when the findings are considered credible. A study is considered credible when those who have had the experience with the phenomena can recognize it from reading the findings of the study (Sandelowski, 1986).

A threat to credibility in qualitative research is the researcher becoming too enmeshed with the phenomenon such that researchers cannot separate their personal experience from those of their participants. In this study the threat to credibility was counteracted by the researcher's statement of assumptions and biases, by the bracketing interview, and by the group process of interpreting participant protocols within the context of an interdisciplinary research group.

Credibility in the proposed study was also sought by having results evaluated by participants. This was achieved by sharing the thematic structure with the participants after the descriptive analysis phase was completed. Results of the study were discussed with the participants to determine if they offered a description of what it was like to grow up with a chronically ill sibling. Participants could relate to the thematic structure presented.

Reliability in qualitative research can be evaluated by its auditability; that is by the ability of another researcher to arrive at similar conclusions given the researcher's data (Sandelowski, 1986). The endeavor of auditability was sought in the current study by having the transcripts reviewed in the Phenomenology Group. According to Babbie (1986) "the basis of truth is agreement" (p. 25). Therefore, the group must agree on the correctness of the interpretation put forth, not simply come to a compromise.

A proposed interpretation can be altered or discarded when evidence of a more correct position is provided (Wertz, 1986).

Summary

An existential phenomenological interview was used to obtain a first person description of the experience of growing up with a chronically ill sibling. To assure that this description was as descriptively clear as possible, the interdependent procedures of bracketing, intuiting, analysis, and describing were utilized. These procedures kept in abeyance the biases and prejudgments of the researcher, permitting participants the freedom to describe the experience in their own terms. Finally, after the researcher had prepared a tentative general description of the experience of growing up with a chronically ill sibling, participants were invited to evaluate the results. This allowed them the opportunity to offer criticisms and corrections to the thematic structure.

The knowledge derived from this study will be useful to those who work with families of chronically ill children to provide both immediate and preventive care. Most researchers agree that a child's chronic illness will impact, in some manner, on the entire family, including healthy siblings. What is still poorly understood, though, is why or which healthy siblings are vulnerable and what are the outcomes of this vulnerability. This research extends

the knowledge needed to help nurses to know if, when, and how they can assist well siblings and families through the struggles of having a chronically ill sibling.

CHAPTER IV

RESULTS

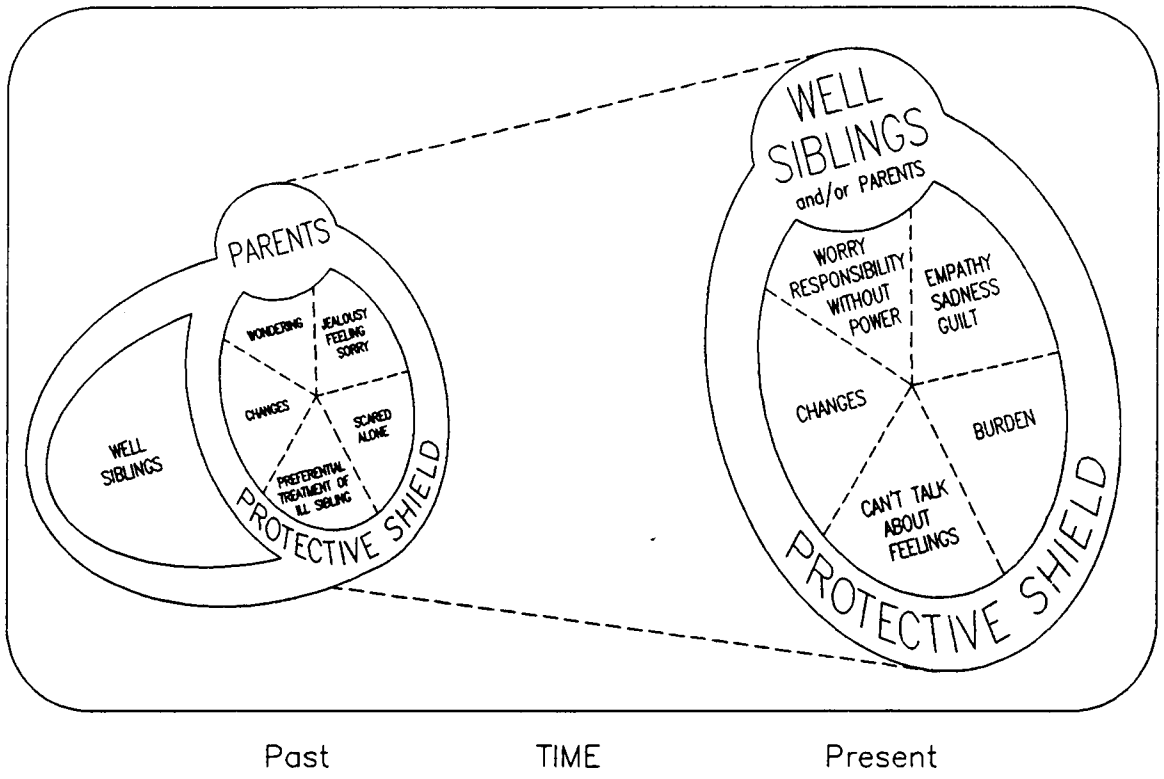
The purpose of this investigation was to develop a thematic description of the experience of having lived with a chronically ill sibling with insulin dependent diabetes mellitus (IDDM). A single basic question - - "Tell me what it was like to have a chronically ill sibling" was posed to 14 adult participants. All participants were volunteers and unknown to the researcher at the time of the interview. Of the total group, 10 participants were female and 4 were male; their ages ranged from 22-45. Socioeconomic status, education, marital status and type of employment varied. Participants' ages at the time of the diagnosis of their diabetic sibling ranged from 1-19 years. The length of time that the participant lived with their diabetic sibling ranged from 1.5 years to 18 years.

Each person participated in a face-to-face interview that began with the above question. Pseudonyms chosen by the researcher were assigned to each participant. After interviews were transcribed, each transcript was thematized. Subsequently, an overall thematic description of the experience of living with a chronically ill sibling was developed. The final thematic description was shared with a number of the participants to elicit comments on the fit with their specific experiences of living with a chronically ill sibling.

Phenomenologically, the experience of living with a chronically ill sibling presents itself clearly in two periods of the participant's life: the past and the present, as represented by Figure 1. These two periods are not distinct and separate, but are interrelated and interdependent; graphically shown by the dotted lines connecting the two periods. The themes of the past provide the background for the themes of the present. Many of the themes of the past are moved forward to the present, but because of the passage of time, are described differently by participants. Graphically, this is shown by arrows connecting the past themes to the present themes.

The themes within each period are also interrelated and interdependent. To illustrate this, the lines between the themes are broken. Experientially, it is difficult to determine where one theme ends and another begins. All participants were more likely to describe their experiences of living with a chronically ill sibling in terms of <u>all</u> the themes rather than in terms of a single, isolated theme.

Participants usually spoke of the past for only a brief segment of the interview and were more interested in relating their experiences of the present. For some, this was because they perceived the present as more stressful than the past.



CHANGES: family patterns, sibling relationships → CHANGES relationships with sibling and mother

PREFERENTIAL TREATMENT OF SIBLING → CHANGES relationships with sibling and mother

WONDERING: How did the sibling become ill? → WORRY/RESPONSIBILITY/ WITHOUT POWER

JEALOUSY/FEELING SORRY → EMPATHY/SADNESS/GUILT

SCARED/ALONE → BURDEN

SCARED/ALONE → CAN'T TALK ABOUT FEELINGS

Figure 1: Thematic Analysis

> I think it is worse now then it was then. Because now you know more about what could happen. . . as the years go by and you realize what could happen. (Joyce)

The metaphor of a protective shield, woven around the diabetic sibling by his or her family, was taken from the words of a participant and occurred in regard to both periods:

> I have always wondered if all this does stem from the fact that he had diabetes. . . they never broke off that protective shield that she always had woven around him wherever he went. On the church trips if he went, she had to go. And I am sure I would probably feel the same way. I am sure it would be difficult to let your child go, knowing that they could face a problem with the diabetes. (Ellen)

Through the themes we gain an understanding of how the participants and family dealt, and are dealing with, the protective shield woven around the diabetic sibling.

Themes in the two periods are as follows:

PERIOD ONE: PAST

1) Changes (family patterns, sibling relationship)
2) Wondering how the ill sibling became ill
3) Jealousy/feeling sorry
4) Preferential treatment of ill sibling
5) Feeling scared/alone

PERIOD TWO: PRESENT

1) Changes (relationship with sibling and mother)
2) Worry/responsibility without power

3) Empathy/sadness/guilt

4) Burdened

5) Can't talk about feelings

The following presentation of results begins with a description of the ground category of time. Next, a discussion of the figural aspects of the experience of living with a chronically ill sibling will be presented. A discussion of the two periods and the themes that emerged will follow. Finally, unique participant characteristics, that were reflected in their descriptions of living with a chronically ill sibling, will be addressed.

Time as Ground

Time emerged as the most universal ground in all protocols. All participants established a temporal context for their stories. Participants mentioned exact ages of significant others and specific seasons of the year.

> I remember it was at Christmas time when he was diagnosed and he was 9 years old. And when he came home from the hospital he couldn't have any of the treats. (Ellen)

> Being 12 I just had no clue what to do or how to act.(Fran)

> I was probably 10 or 11 when I first started giving her shots. (Jean)

> I was about 8 years old when she was diagnosed.(Sarah)

> Halloween is the worst time for candy. I think I remember one time trading him out. I made him up a bag of sugar free candy and traded him out for the regular stuff. (Eric)

> Ever since that Christmas that he was in the hospital he has taken extremely good care of himself. He has been doing real good ever since. (Fran)

Participants also noted that the passage of time has led to changes in themselves and in their relationships with significant others. Some spoke of time in relation to "before" and "after" the diagnosis of their sibling. The following examples depict these themes:

> Before he was diagnosed he was real grumpy and we were arguing a lot more than usual and he was having to get up at night to go to the bathroom a lot. Like I said I remember his appointment was around Christmas time and we were over at my grandmother's and he was playing with a little pool set that he had gotten for Christmas. The three of us were playing with it and if he would lose he would get real mad and throw his cue stick down and everything. And I remember mother putting her arm around him and saying we have an appointment this week and we are going to try to find out what is troubling you, what is bothering you. (Ellen)

> I think I felt sorry for her at first. I think I would give in to an argument. You know if we had a fight or an argument I would give in to it. And that wasn't a natural reaction because we always got into it, if there was some disagreement we certainly held our own. To the point of dividing a room, you know, you don't cross or whatever. But I give in to her in that manner. . .before she was diagnosed we were pretty much on an even basis. (Beth)

> Actually it may have made us closer. I have never thought of it that way. That with me knowing that she would need care and knowing that I would be there. . . sharing the knowledge we didn't have when we were younger about disease, about what happens to the body with disease, mentally, physically, that sort of thing. So that is a common ground for us. (Beth)

> When you get older, in most cases, I think family becomes more important. When you are growing up you don't appreciate them as much. Even through high school and college years they are not as important, as you get older. (Tyler)

For some participants the passage of time makes them aware of the possibility of their sibling's early death. Participants describe death looming with the passage of time:

> I just felt then that he is going to die at an early age if he doesn't watch it. . . I just don't want him to die at a young age. My dad did. (Fran)

> I know when you are diagnosed, what I found out that the earlier you are diagnosed, the less chance you grow older. That really frightens me. (Tom)

For others the passage of time resulted in the giving up of hope. Hopelessness was experienced personally or was the participant's perception of how their diabetic sibling felt. The following excerpts express this theme:

> I would hate to wish diabetes on anybody. Who wants a disease like that. Most diseases have a cure, this is one that doesn't . . at this point I don't think it will be in her life time. (Beth)

> I think her being so ill these few times this past year has shown her that no matter how hard she fights she is not going to live physically as long as everyone else. I don't know if she ever thought of it that way before. She doesn't show her emotions, she doesn't talk about her emotions so I don't know if she ever would tell you that she felt that way, but just by her actions and her reactions to things shows me a different side that she probably hasn't even let herself see yet. (Sarah)

> Diabetes has depressed her down through the years a lot. She feels like she is so much different than everybody else because of it. . . She has mostly been depressed after she has gone into diabetic shock and has come out of it. She thinks then, that she has lost some of her brain cells, and that she is gradually going to get worse and things like that. (Tyler)

> In one day M ate 7 bags of M&M's. Just that I counted and who knows when I finally started to count these things. And finally I said M what are you doing. She says, 'I can do what I want to. I can adjust my insulin to how I need it.' I'm like, 'that doesn't

> matter, you had 7 bags of M&M's' and, she just says 'leave me the hell alone, L. It is my life.' I can't, you want to tell them and bring things to her attention just so maybe it will register, but I honestly thought that she doesn't care. . . to me, she just doesn't care. At one point in her life, a couple of times I think she probably feels 'what does it matter?'. . There for awhile she was bound and determined to help find a cure and I think she really has given up because nobody else has found anything, why should she keep going? (Carol)

> I probably feel like sometimes that she just don't really care anymore. . . You take your shot, you're up already, why don't you get yourself something to eat and then you can go back to bed. (Meg)

Anger was sometimes expressed in response to the participant's or their sibling's hopelessness:

> She'll say just crazy things like, 'Well, if I go hypoglycemic, just let me die.' You don't, that is not reasonable. I don't know why she does that, but she does. . . It makes me very angry. Because I can not see someone having a child and talking like that. . . I tell her she needs to think about her son. Leaving her husband. But if she is hypoglycemic, whether she likes it or not I will be calling an ambulance for her. Basically I let her know that I am going to be there and that she is going to be alive whether she likes it or she doesn't. If there is an ounce of life left in her, I am going to get her back. (Meg)

> I always feel angry at God for giving her that life. She started out with all the expectations that we all do. And you wonder why she was targeted to have such a bad time down here. When everyone else's life is happy go lucky. . . You can't help being a little irate and saying no she has been through enough and it is time to stop. Either take her away or quit punishing her. It is kind of like you feel like she is being punished for something she never did. It is hard to understand for me. (Sarah)

The passage of time was experienced as important for many of the participants. For some it taught them the importance of taking one day at a time. For others it was

seen as a vehicle of adverse things to come. These themes are expressed in the following excerpts:

> You just have to deal with it, day to day. (Joyce)
>
> You have to take day by day and make the best of it. Just go with what you got. Make the most of what we have while we have it. . . I guess just day by day and see what the future holds. (Tom)
>
> I worry a lot about him now because he is getting older and the long term effects that this disease has had on his body which can cause blindness, heart disease and all these other things. I keep wondering, you know, if he might possibly have problems like maybe kidney failure or something like that, amputation that leads to an injury that doesn't heal. . . in the long stretch you can't help but worry about what will be. (Ellen)

Situations that were Figural

Although the purpose of this study was to arrive at the overall thematic description of the experience of living with a chronically ill sibling, it was also important to note those situations which tended to be figural for the participants. These situations are important in understanding the experience of having a diabetic sibling. These included: 1) Time of diagnosis, 2) A medical crisis of the ill sibling, 3) Observation of the ill sibling giving him or herself insulin injections, and 4) Meal time/diet restrictions.

Time of Diagnosis

Many participants vividly recalled the time of diagnosis of their ill sibling as a time of crisis for themselves and their family. Participant's descriptions contained graphic details of the symptoms of the ill child,

going to the hospital, and how they were feeling. The statements below illustrate this:

> She was always going to the bathroom. Always thirsty...She got real skinny. (Karen)

> We took dance lessons and we were having a dance recital. . . and she had her leotards and tights on and she was skin and bones and my grandmother had talked to my dad about it. She said she didn't think that she looked at all healthy. And I guess it took daddy seeing her like that in leotards and tights, maybe, I think he realized that she really was sick because she was so skinny. (Jean)

> She had lost a lot of weight, a tremendous amount of weight. She was drinking a tremendous amount of water and she was not getting enough sleep. Her grades had dropped. They dropped tremendously. Mother had taken her to the doctor. . .they diagnosed her with diabetes. It was a major shock to the whole family. . . I can remember crying all the ways to the hospital. . . They rushed her straight to Children's. (Tom)

> She laid in bed for about a week. The doctor kept telling my mother that she had the flu and then she went into a coma, I think. They decided that she was a diabetic.(Joyce)

After the initial crisis, though, most participants perceive that their lives returned to a normal routine.

> The first conflict for me was seeing my father upset over it and she (diabetic sibling) was devastated over the fact that she would have to take that kind of medication. So that was the first realization that something was definitely wrong. Seeing her cry and being so upset was naturally upsetting to me. . . My fear is that this is something greater than I can deal with. That it is something greater than my dad can deal with. That we are not going to be able to work this out like we usually do within our family. And that is where our strength had always come and how we had always worked problems out. So this was something bigger than us that we had to adjust to. . . But then after she started giving herself her shots and it became just the norm for her life, things just kind of evened out and it was okay. . . Life at home changed very little except for me seeing her give herself a

> shot and knowing that there was an extra meal being prepared.(Beth)

Medical Crisis of the Ill Sibling

The routine of the chronic illness became unremarkable for most participants; that is, until their ill sibling has a medical crisis. This situation was clearly articulated by Fran:

> Really, when I am around J or when I was around dad, I never even think about it. A few years after J had it, it is really something you don't think about, you really don't get angry about anything, you just, you know until they go into a reaction it is like it is time to wake up and realize that he is a diabetic. Then a few weeks down the road you are back being yourself again, just like they don't even have it. Because I always try, I don't know, I don't ever make him feel like he is a diabetic.

Participants described in great detail a medical crisis of the diabetic sibling. Listen to the number of details in Beth's story:

> I can tell you the first time that she went into insulin shock. She was diagnosed in the spring and it was the summer, and we spent a lot of time at the farm with my uncle and aunt. We worked with them outdoors a lot. It was manual labor, but it was fun. We enjoyed it. We had gone down to the building, it was a smoke house, and we thought it was great that we were girls and we could get out there and we could work with him. So it was the two of us, my sister and myself, he and R, who lived on the farm and worked there. We were building. We worked and we had lunch. It was the middle of the afternoon. And my sister usually didn't get very high on the building. I was the one that would get high and do the work up there. All of a sudden she is on the ladder, up on the top of the building, and we have a plank stretched from one side to the other. It is all open, it is just a frame. She is in the middle of the plank, jumping up and down and the plank is giving. We think, 'oh my goodness, it is going to break and she is going to hurt herself'. So my uncle asked her to come down. She refuses to. And you start to see a character change, a personality

> change, because we never disobey him. If he wanted us to carry rock, we carried rock. So I asked her to come down. And she refuses. And she runs from one end to the other on the plank. And it is ten feet off the ground. And finally he starts up the ladder to bring her down. She takes the ladder and throws it off the building. So he can't get her. I don't know what is going on. I just know it is different. So finally R asks her to come down and she starts coming down a little bit. And it dawns on me that she needs some sugar and there is something going on here. She is screaming at everybody. I run to the house and I can't find sugar, but I find syrup. So I run back with the syrup, and by that time they had gotten her off the building. My aunt and R are trying to lead her to the house and she collapses. But I get enough sugar on her, in her mouth, that she begins to come around and become coherent.

For some participants it was during the medical crisis of the ill sibling that they first became aware that the illness could be serious. This awareness for some was early in childhood; for others it did not occur until adulthood.

> I just got real scared because I didn't know what was going to happen or when the next one was going to happen or how serious the next one was going to be or if he was going to have anymore, anything like that. It is just, it just sort of wakes you up. (Fran)

> That was the first time I saw what could happen to her and how out of control and how lacking in judgment she could become. (Beth)

Karen, who was 7 years old when her 13 year old sister was diagnosed, was a college student before she realized that diabetes can be a serious illness. She describes clearly how she came to learn of the seriousness of the illness:

> She was hospitalized when she was pregnant. One of the radiologists I was working with told me that some women can spit out babies every year, but diabetic women can't. Your sister may or may not make it through this. He scared me to death. I just thought, I had

> never, it had never occurred to me, maybe that is when it really occurred to me that she had a serious illness. Because that is when I realized that she just can't do everything that everybody can do. She has to watch other stuff. . . I thought she was going to die. I thought she was going to die before she had the baby, or immediately after. I just didn't know. She was in intensive care and everything. . . It was frightening for me. Of course I love my sister very much, and I certainly did not want her to die because she happened to get pregnant. So yes, it was very frightening for me to find out or for me to realize that what she had was not just my sister has diabetes. That it was actually a problem. . . I had this new knowledge that she was not only not in town but she might not be around. That can be true for anyone I realize that, but with her I realized she had a physical thing that could cause her life to end very quickly.

Observation of Ill Sibling Giving Themselves Insulin Injections

Observing or knowing that their diabetic sibling must give themselves insulin injections was another situation that was figural for many of the participants. Both Beth and Jean associate insulin injections with the seriousness of the illness.

> The first time I knew about the shots I knew she was really sick. (Beth)

> Knowing that she had to take those insulin shots everyday, sometimes twice a day. I think that is what makes you really aware, knowing. . . She is just like you and me, but she still, she is the one taking shots every single day. . . I think taking the shots, just knowing that was, something she had to do, that is just what made me aware. . . knowing that she takes the shots to stay alive every day. (Jean)

Tom and Eric are scared of needles and doubt if they could give themselves injections.

> I am terrified of needles. I have been since birth, I just can't stand needles. I am very proud of her that she can overcome that and just give herself a shot

> wherever and whenever needed. . . .I told her that I don't know how you do that, but I guess when you have to do something to survive it makes a big difference. (Tom)

> I think I am just glad I don't have to give them to myself. I don't much care for needles. . . I wouldn't want to have to go through something like that everyday. It does not look like something that would be enjoyable. (Eric)

Ellen believed that her brother's independence was restricted by the necessity of having to take insulin injections.

> We worried about his field trips. He wouldn't get to go if they were going some place where my mom couldn't meet him. He might not be able to get his shot or something like that.

Meal Time/Diet Restrictions

The final situation that was figural for many participants were the dietary restrictions of the diabetic sibling. All participants were well aware of the dietary restrictions of their diabetic sibling. One participant helped her ill sibling cheat.

> I helped her cheat. Because I knew I couldn't do what she was doing. I couldn't do without candy bars all the time or ice cream. And here again it was ignorance partially by not knowing how damaging the food would be. I knew she shouldn't have it. I don't think I understood what could happen if she did have it. (Beth)

Another participant recalls using food restrictions as a means of getting more sweets for himself. For example, Eric would eat all the candy at Halloween time to prevent his brother from eating any sweets. Carol believes that the dietary restrictions increased the sibling rivalry between

her and her sister. She recalls getting into a fight with her sister about the diet restrictions:

> We had got in a fight on the school bus. She was eating a chocolate chip cookie. Getting off the bus I was fussing at her for it, 'you are not supposed to be doing that.'

Other siblings felt very empathetic towards their sibling's diet restrictions.

> I felt that I had to really change my life style to make him feel not so out of place. It changed the way I ate. I felt I shouldn't eat sugar or candy in front of him. I didn't want to make him feel that he was out of something that I could still do, eat candy and sweets. . . I just felt that it was my duty as a sister, you know, change with him. (Fran)

Jean had a fear of eating a candy bar in front of her sister because she was concerned about how she would feel and didn't want her to resent her:

> I didn't want to make her uncomfortable because I know how it is. . . I was afraid she would feel that way because she loves, loved, still loves to eat candy, sweet stuff. She could have things like that every now and again but not like I could have them. I hated to make her feel uncomfortable or resentful towards me, because she had to eat a certain diet. . . I was just afraid that I would make her want to give in and eat the things that I eat. . . I didn't know how much will power she had. . . If I did eat candy or something I usually would go in the other room or something like that.

The above situations are figural for this group of participants who were all siblings of a diabetic. It was at these times that most of the participants became aware of the seriousness of the illness or observed that their sibling was different.

Major Themes

As described in the previous chapter a hermeneutical approach was used to analyze the present set of interviews. A thematic description of the first person experience of living with a chronically ill sibling was distinctly divided in two periods: the past, and the present. The themes that emerged from participants' descriptions in the first period were: 1) Changes (family patterns, sibling relationship), 2) Wondering how the ill sibling became ill, 3) Jealousy/feeling sorry, 4) Preferential treatment of ill sibling, 5) Feeling scared/alone. Themes characterizing the second period were: 1) Changes (relationships with sibling and mother), 2) Worry/responsibility without power, 3) Empathy/ sadness/ guilt, 4) Burdened, and 5) Can't talk about feelings. In describing each theme exemplars from the various protocols are used to provide the reader with a greater understanding of the experience of having a chronically ill sibling.

PERIOD ONE: PAST

All participants were able to reflect on the past and relate what it meant to them to have a chronically ill sibling. Some participants initially stated that they could not remember anything, but then went on to give vivid details of some situation, event, or feelings. Below is a discussion of the five themes that emerged in reference to the past.

Changes (family patterns, sibling relationship)

Several participants experienced the diagnosis of their diabetic sibling as precipitating many changes and disruptions in their lives. Many of these changes were perceived as negative although some also were viewed as positive. Changes that participants were most cognizant of included changes in family patterns and the sibling relationship.

Changes in family patterns: Participants described how the diagnosis of their ill sibling changed their family's daily patterns. The following excerpts describe some of these changes and the participants feelings regarding these changes:

> When M became a diabetic we all became diabetics and we all changed everything about us. We all ended up having to wear shoes outside. . .we couldn't do a lot of things because of having a diabetic in the family. Cost was a big factor in it, with having so many children in the home, plus having a diabetic. Family vacations were no more. . . A lot of people talk about the family vacations, we never had that after all this. . . We had to cut out a lot of things. . . I had to watch what I did and change my routine. (Carol)

> I love breakfast and we got up every morning to a complete breakfast. . . it was a good change. (Carol)

> It changed all of our lives. You just can't get up and go like you would like to or even out to eat when you want to. It is all on a set time schedule so there are certain things she has to eat. It was sort of almost a pain because, I guess it is never a pain when it is a loved one, but it is inconvenient. You always have to think of snacks, meals, on down the road. You always have to pack, looks like you are taking everything but the kitchen sink with you. (Tom)

> In the beginning I thought it was a very frightening thing. I felt like it was going to change our whole

> life. I didn't feel like our family was ever going to feel normal again, because we always had to be on this schedule and if you got off the schedule then it would mean that J would have one of these attacks. When we even went on trips we had to pack the insulin. (Ellen)

After the diagnosis of their diabetic sibling, participants perceived dietary changes as requiring the greatest modification in their daily patterns. These changes were perceived either as being made voluntarily or being forced on them by a parent. The following comments present these themes:

> You didn't walk in with a box of donuts and eat them in front of her, that type of thing. We tried to be pretty consistent about not doing something like that in front of her because we knew she would want it and couldn't have it. (Mark)

> In the beginning we just didn't buy anything like that (sweets). S and I didn't eat it either because J couldn't have it so we just didn't get it. . . Mother never made desserts anymore, we never got pies, we never got cakes, we never baked cookies. I am sure I kind of missed that. (Ellen)

> Mom fed us all like we were all diabetics. There never were any sugary things in the house. We never had cokes. My mom never fried anything. She baked everything. (Karen)

> The whole family's diet changed at that time. When I did eat at home you did notice the food being a little more bland than normal. (Mark)

> Everything was sugar free from then on. There were times when mother cooked a cobbler and we had sugar free cobbler and regular cobbler. (Carol)

Participants described various family patterns that they perceived as changing or occurring in response to the medical diagnosis of their ill sibling. These included:

1) Vigilance of the diabetic sibling, 2) Minimizing the diagnosis, 3) Working together and sharing responsibility, 4) Routinizing and keeping the illness in balance, 5) Maintaining the family secret, and 6) Over-vigilance of the well siblings. Examples of these patterns are given below.

Vigilance of the diabetic sibling may be noted in the following statements:

> We singled her out, we tried to figure what was wrong. (Carol)
>
> I remember he was younger than me and I was protective of him at school and I know that we would always worry if they were having a party at school or something and they would forget to bring something he could eat or they would forget to tell my mom that the party was going to take place. And we would worry that he didn't have anything to eat when the other children were having something to eat, a snack in the classroom. And we were always checking in his bag to make sure that he had his little sugar cubes that mother packed in aluminum foil or a mint or something in case he felt, we called them weak spells coming on. . . . at school I remember we went to school together and I always looked after him. I tried to make sure he had everything he needed. . . . I would worry about him getting hurt at school or I would worry about him having one of those weak spells . . . You know I was afraid if the teacher did not notice it or did not realize what was happening it could get real severe and he would have to go to the hospital. . . . And as he got older we worried that sometimes when he took tests and things like that he was not performing at his best level because maybe sometimes his condition was interfering with his performance in the classroom. And we worried about that too. (Ellen)

The following excerpts depict minimizing of the diagnosis:

> I have a brother who just happens to be a diabetic, it is no big deal type of attitude. There are things that could be a lot worse than being a diabetic and I am

> just thankful that this is something that he can take care of and keep going. At least he doesn't have cancer and have to go through chemotherapy and anything like that. . . When I see someone that has something a lot worse than having diabetes, than diabetes seems like nothing to me. Even though I know it is. (Fran)

> When they put him in the hospital for tests and everything, in the beginning they thought he had leukemia and of course my mom and dad, I'm sure, were very upset. . . we were really kind of relieved when we found out that it was diabetes because it was something that could be handled. . . We have always realized that we were lucky that it was not leukemia, it wasn't any form of cancer. It was something we could live with. . . I remember asking mom if he was going to die and she said no. That this was something that could be controlled. (Ellen)

Some participants remember their family dealing with the diagnosis by all working together, sharing the responsibility to help. One participant describes the cooperation in her family:

> It was just a lot of things that had to be dealt with and we all pitched in there together as a family and tried to help with that. I certainly wasn't given more than my share of responsibility, probably any at all, other than the fact when my mom worked we were all there together and I just felt that I needed to pay attention to him and how he was feeling. . . we were all protective of him. (Ellen)

Other participants perceived their family managing the illness by routinizing it and sharing the responsibility.

> It is one of those things that you kind to have to balance. You don't want it, you have it, you have to learn to live with it. (Eric)

> We tried not to let the illness affect day-to-day living. (Mark)

For some participants the illness became the family secret.

> I was a little more quiet. In fact I didn't want anyone to know that anything was different. I just sort of secluded myself, you know in school. I still went to school and everything. I was a little quiet. I just didn't want people to ask me a lot about something I didn't know anything about. So I just really kept it to myself. I didn't open up to anybody, other than mom. . . He never wanted any of his friends to know that he was a diabetic. I knew what it meant to him to keep it within the family. He didn't want everybody to know that he was a diabetic because he was afraid that he would be treated differently. So I kept that pact between us. That is what he wanted. (Fran)

> She was the type of person that always felt that was one of the worse things in the world that could ever be. She always wanted to be normal and she didn't think she was normal with that. She didn't want anyone to know about it. None of her school mates or anybody knew about it. Just the doctor, and we did. She wouldn't carry anything on her or anything like that. So I had to be more quiet. I had to remind myself all the time not to say anything. I am the type of person that I'll talk about anything. Other kids at school might have diabetes, and we had some, but she didn't want anybody to know about it. So I had to be on my guard on that. She kind of wanted it not to exist. It was something you didn't want to bring up or anything like that. (Tyler)

Finally, for some participants, they felt that the diagnosis of their ill sibling resulted in their having to be frequently checked for diabetes, either by a doctor or by a parent. The following passages describe this theme:

> The doctor used to give us the test strips and we would urinate on that and check our sugar levels and all that, make sure we did not have sugar in our urine. It was a possibility. . . Mine was nice and purple, the way it was suppose to be so I didn't have a problem. I was real tickled that I didn't have the problem. . . I can remember standing there thinking, Oh I hope this comes out the right color because I don't want to have to go to the doctor and go through all this stuff J has had to go through. Of course mine was fine. Someone up there must like me real well. (Mark)

> Mother took us all back there and we each had to pee in the jar and she tested every one of us. It wasn't just

> her. She tested each and every one of us for it. I can remember that like it was yesterday. (Carol)

From these examples it can be seen that the participants perceived their family patterns changed in response to the illness. Patterns that existed previously were disrupted, and new ones constructed. These new patterns marked the beginning of the participant's perception of how the family would manage the illness from that point on.

Changes in sibling relationship: The level of impact the illness had on sibling relationship, at the time of diagnosis, varied a great deal across protocols. In most cases, those who were younger at the time of diagnosis did not relate the experience as having a significant change in their relationship with their sibling. A few participants, who were in their teens when their sibling was diagnosed with diabetes, were cognizant of changes in their relationship to their now ill sibling. Some felt that the diagnosis brought them closer; others felt more protective of their sibling. The following examples illustrate these changes:

> Emotionally it was, I guess we got a lot closer. . . We have always been close but the disease will make you bond. When you put that much time in learning something you automatically feel stronger or bonded, more bonded to that person whether you want to or not. . . You feel more bonded than you did before. . . I just feel a little more bonded. (Tom)

> We didn't always get along but that sort of brought us closer together with that happening to him. . . we were able to talk to each other more. We didn't talk about

> diabetes but we just became friends, over brother and sister. I guess we started a friendship. (Fran)
>
> We quit picking on her about that time. You know how the oldest kid tries to pick on the youngest one, bumping them, hitting them, pinching them, stuff like that. Nothing out of spite or hate, it all is in a friendly gesture. I pretty much cut that out with her because I didn't figure she could take it. I looked out after her a little more. Probably got more protective of her at that time. (Mark)

For these participants the diagnosis alone redefined the sibling relationship. For others a significant change in this relationship was not recognized until some years later.

Wondering How The Ill Sibling Became Ill

A second theme participants described during this period was wondering how the ill sibling became ill. Participants needed to discover who in the family ancestry had diabetes; or as one family said, "who was to blame".

> It was a major shock to the whole family because she is the first one on either side of the family, as far back as we even great, great grandparents. . . there are no diabetics. . . At the time we knew none of our family was a diabetic. We hadn't done the extensive research like we have now. We just couldn't understand how it just triggered all of a sudden. (Tom)
>
> We can't find any other traces of diabetes in my dad's side of the family. He is the first one to get it. It's like why does this have to happen to my family? (Fran)
>
> He was diagnosed when he was 18 years old. My father, we are assuming he got it from my father. My father was diagnosed when he was 12 with insulin dependent diabetes. . . But his (sibling) reaction to diabetes has never gotten out of the grieving stage. He has always been real angry and not necessarily at anyone but daddy. It is real displaced anger. . . J blames daddy for his diabetes, so there has been a lot of friction there. You know, it is totally irrational. It is not, I don't even think it is a conscious decision on J's part. He just, it is just always

> someone else's fault. You know, instead of it is just the cards you are handed, this got to be someone's fault. So it may as well be dad's. Because that is probably where I got it. (Amy)

One family, who was unable to uncover anyone in the family tree who had diabetes, formulated their own theory of the illness. One participant described her mother's proposed cause of the illness as follows:

> She thinks that because we don't have a history of juvenile diabetes in our family at all. . .J had scarlet fever and mumps and something else all in the same month when she was real young. Seven or eight years old. She had these viruses, illnesses right bunched up together and mom feels sure that something about having those three illnesses right together; scarlet fever and mumps and I can't remember what the other one was, chicken pox maybe, all within a few weeks of each other all had something to do with J developing diabetes later in life. I have no idea if that could have had anything to do with it or not. But that is my mom's theory. (Carol)

Jealousy/ Feeling Sorry

The third theme concerned participants feelings of jealousy towards their ill sibling and sorrow in regard to their diabetic sibling and/or parents.

Meg acknowledges being jealous of her diabetic sister.

> I think it was harder on me because I was at the age that I didn't understand. I think that a lot of it might have been jealousy because she was always getting toys, so forth and so forth when she was in the hospital. I didn't get the attention that she got. . . Even though I loved her so much, I still felt the jealousy.

Carol believes she was jealous of her sister because she got everything she wanted since she was sick, and, as a result, it increased the sibling rivalry between them.

> She was so called spoiled, I guess, anything she wanted, she got. She was sick. She was in the hospital. If she asked for something, she got it. That is how it became. . . I think I had a little jealousy. She was getting catered to, pampered quite a bit and that was a little bit of jealousy. . .she was singled out very much. And that was really hard on me. I had a lot of jealousy towards her there. A lot of anger to where she and I fought like cats and dogs there for the first two or three years. We didn't get along at all. Everything was a fight. Even who was going to the bathroom first.

Karen believes that she too was jealous of her diabetic sibling. She related a story about when her diabetic sibling had a hypoglycemic reaction as a child during a rafting trip:

> J got low blood sugar, of course, in the middle of the river. Somebody in another boat had some candy and they threw it over to us. My mom was yelling, 'do you have any candy?' And they said, 'yes' and they threw it over to us. At that point I felt a little jealous that J got to eat this candy and I didn't.

Some participants felt their jealousy and resentment abated because of feeling sorry for what the ill sibling and/or parents had to endure. The following examples depict this theme:

> We figured we gave up everything as far as sweets in our house. . . a small price for me to have to pay for what J was having to go through. . . I think I was so grateful I didn't have to have the shots and that I could eat what I wanted to, I think that is what balanced the scales. I think that is why I didn't feel like I was being neglected or anything like that. I felt fortunate that I didn't have to put up with what he had to put up with. (Ellen)

> Coming to the realization that they (parents) are hurting and they are not dealing with it as effectively, that was making it worse. That was probably the worst. The worst part of it. (Amy)

> I just remember thinking that was so sad and seeing how sad my parents felt. And how I am sure they worried about him. It made me feel sad and it made me feel concerned because we were a very, very close family. . . I felt sorry for my mom and dad, and I guess I would just think that I wish there was a cure for it. And in my home life I just held on to the hope that they would find a cure for diabetes. . . I always felt sorry for mom and dad because I knew they were sad that he was having to live with this. . . I only felt compassion for my parents because I knew how much they worried about him. (Ellen)

Preferential Treatment of Ill Sibling

The fourth major theme concerned the fact that many of the participants perceived their diabetic sibling as receiving favors or special treatment as a result of their illness.

> I knew she always got preferential treatment, but that was because she was diabetic. I think I just mentally knew that you felt sorry for her because she had to take shots. She could not eat like we were eating. So it was okay that she got some extras because I am getting a lot of extra that she isn't. When we got our cars, I took whatever I got. They bought the car and brought it to me. She goes and picks hers out. You know by this time she had been getting little extras all along, so it was expected, you know, that she won't have this car. And she didn't. I want this, this, and this. . . Clothes, mom usually made our clothes, but not for her, she had to have some bought. (Beth)

> When R was 16 she got a car and it was a bomb. When P was 16 she got a car and it was a bomb. M (diabetic sibling) had four cars and she wrecked everyone of them. When it got to me and I wanted to pick out my bomb I said, 'I am the baby, I want to pick out my bomb.' They were 'no way'. (Carol)

Karen felt that her sister used her illness as a means of getting out of punishment.

> When we were all lining up for ours, or I was, for our spankings, J only got one or two whacks to my five because she was going 'oh my shot'. She got out of

> punishment completely. . . Looking back on it I still think I was treated unfairly.

Ellen is aware that her brother received special treatment and favors as a child, and was treated differently at meal time. She recalls her brother getting out of chores and being babied by her parents:

> My dad would never let him mow the lawn or trim or anything like that because they were so afraid. He was always kind of babied because my parents were very protective of him of course. . . Lots of times at meal time he had to have different things because his food had to be prepared in special ways. I do remember sometimes that I thought that his food looked better than mine. I would think 'Gosh I wish I could have that.' I would think his looked a little better than mine looked. He would get something grilled in the oven and we would be having beans or something else like that.

Although many participants perceived their diabetic sibling as receiving special favors and treatment, few reported harboring any long-term resentment. For the most part such "special treatments" were understood as a result of, or compensation for, the illness.

Feeling Scared/Alone

The fifth theme concerns the feelings of being scared and alone. As adults, many of the participants still remember feeling very scared and/or alone during their childhood as a result of their sibling's illness. Participants often vividly remembered being alone and scared when their sibling was first diagnosed or taken to the hospital. Many feared that their sibling was going to die:

> They took her in immediately. She was apparently pretty bad off. That was really scary. I got home

> from school and nobody was home. That was really odd. That was real odd. (Carol)
>
> I had no idea whatsoever what diabetes was or anything and I wondered if he was going to die. I didn't know if it was a very threatening type of disease or anything. . . Being 12 I just had no clue what to do or how to act. My main concern was how he was doing and if he was going to die. (Fran)

Meg remembers her sister being in the hospital a lot and being left with relatives. She perceived this as being left alone, without immediate family support, sometimes wondering if her sister was going to live:

> They were gone really the whole day and that is the one thing that sticks in my mind. . . I was left by myself wondering if my sister is going to live. . . I would be picked up at school by aunts and uncles and just took home. Of course they would stay with me because C (ill sibling) would be in the hospital or whatever. . . She would be in the hospital and there would be no one there. I would have to get on the bus by myself. . . It is like you have no one to turn to then. Everybody is gone. . . It was real distressful because friends, they always had their family there and their brothers and sisters. Whereas mine, my sister was constantly in there, the hospital. And my parents, they were working or at the hospital with her. It was real distressful for me. And I grew up more or less constantly worrying.

Despite the lack of communication in her home, Meg knew what was going on and it upset her to have no one to talk to.

> You know a child, a child really knows more than what you think they do. Because I knew. . . I knew that she was real bad off. I knew that the way she had been, hypoglycemic for so long, that they had to keep her in the hospital and I was just really upset. I knew that something was going on around me because I could feel the stress coming from my mother and father. I was just really upset yet I had no one to talk to. . . It is really hard on a child because everybody around them thinks that they don't understand and they do.

Most participants felt ill prepared for their diabetic sibling's first hypoglycemic reaction, and remember being very frightened when they observed their sibling in a hypoglycemic reaction. It was during these times that many of the participants feared that their sibling was going to die.

> The first time he had an insulin reaction. . . That was first time, I didn't know much about insulin reaction, but I knew at the time that you could slip into a coma. I don't know, it's just, at that time I didn't know if I was going to lose him or that he was going to die or what. (Fran)

> It was kind of scary because I did not know if she was going to wake up or not. (Joyce)

> It was like someone being drunk or something. She just couldn't do anything. Her eyes would roll back into her head, she didn't know where she was. It is just, you see someone like that you just think that they are not going to come back, if they are going to snap out of it, or if they are going to go in a coma or something like that. . . She wouldn't wake up in the morning, mom couldn't get her up out of bed. Of course mom knew to give her orange juice, or something that had some sugar in it, to bring her out of it. It was a scary time then, because you wondered if this was going to work or is she going to have to go to the hospital or something like that. . . it is a tense situation until she. . .comes out of it. . . it is scary. You don't want to lose your brother or sister or whatever. It makes you think that you might lose them, there for a second. (Tyler)

> I think the main thing I would remember is concern for him and there was a lot of anxiety at the beginning out of fear that something was going to happen, because at the beginning he had a lot of episodes of insulin shocks and that was a very scary experience for me. . .I would feel so sorry for him because he would think we were trying to hurt him and he would do anything to get away from us. He was just like a scared animal. You would just have to physically get a hold of him and get something into his body. I was always in a panic to do that because I think if I don't get it into his system then he is going to go into a coma and we are

> going to have to get him to the hospital. I felt responsible. (Ellen)

Carol vividly describes seeing her sister's first hypoglycemic reaction.

> I honestly thought she was possessed. When I saw her having a seizure I really thought she was possessed. I didn't know what it was. Actually I ran and hid from her. I locked myself in my room and hid from her. I think that was when I really decided, thought about life without her. And I couldn't imagine it. I don't, I don't remember a whole lot about it. I just remember it really scared me. I didn't know what it was. Didn't know anything about it. I'd never really seen a seizure. I read about them but never really thought a whole lot about it. It was just really scary. I just remember how white she was and all the blood. She bit her tongue. There was a lot of mucus. Just everything. It was just real scary, real freighting. I didn't know anything about it.

Tom explains that he was so scared about his sister's reactions that he began to shun her.

> I would overstuff her with food when she would get low. I would just say 'eat this, eat that.' It scared me so I backed off. I didn't do as much activities or take her as many places as I used to. . . . I would shun her. . . . Because when she would go low it would scare me and I didn't know how to really handle it.

The fear concerning a sibling's hypoglycemic reaction was not only based on what could happen to the ill sibling but also fear for oneself because of the diabetic's behavior. One participant recalls:

> He would always run from us like we were trying to hurt him, his vision would be impaired and he couldn't see and he would fall. He would throw things at you. I know one time he threw the phone at me and it hit me in the ankle. . . . He would break a lot of things in the house at times. . . . One time he fell down the basement stairs, or one of us did. We may have fallen down the stairs together because I was trying to get out of there. (Ellen)

The above examples have shown that when a person talks about what it was like to have a chronically ill sibling, many feelings are expressed. It is clear, though, that the predominate feelings were those of being scared and alone.

As we have seen from the past themes, the illness brought many changes and disruptions in the lives and family relationships of the participants. For most, these changes were perceived as being both abrupt and unending. The past themes overlap and are interrelated, one influencing the other. For example, although participants felt jealousy towards the ill sibling, resulting from their perception of parental preferential treatment of ill chid, they also lived with the fear that their ill sibling might die. As a result of this fear participants are cognizant of how vigilant and protective they and the family became of the ill sibling. This vigilance and protectiveness of the ill sibling, that began in childhood, continues and intensifies even as the ill sibling enters adulthood. Some participants also feel a shift of responsibility for the ill sibling from parent to themselves.

The past themes set the stage for the present themes. Many of the past themes are moved forward to the present, but described and experienced differently by participants. This relationship between the past and present will be explained in greater detail after the present themes are presented.

PERIOD TWO: PRESENT

The themes in the present offer us an understanding of significant changes brought about in the participants' lives as a result of their sibling's chronic illness. Analysis of the interviews revealed that all participants, as adults, are even more personally affected by the chronicity of their sibling's illness. The themes of the past are brought forward and are reflected in the present themes. As adults, most participants are more acutely aware of the severity of the illness, feel a greater responsibility for the care of their diabetic sibling, experience feelings of empathy, sadness, and guilt, and feel an inability to express their true feelings. In reference to the present, five themes emerged: 1) Changes (relationship with sibling and mother), 2) Worry/responsibility without power, 3) Empathy/sadness/guilt, 4) Burdened, and 5) Can't talk about feelings.

Changes (relationship with sibling and mother)

Participants described changes in their relationship with their mother and sibling, resulting from the chronicity of their sibling's illness. Some participants perceived that their diabetic sibling, as an adult, still receives special treatment from his or her parents. Ellen perceives her brother's children being treated more favorably than hers. As an adult she is both resentful and angry of his children's special treatment by her mother:

> Sometimes I feel that her relationship with his children is closer than her relationship with my children. And there again I think it is because he is so dependent on her and she helps him more in every way than she does my older brother and me. . . She doesn't love my children any less and she would do just as much for them but she wants to be needed and dependent upon her. I don't depend on her like my younger brother does and I never have. I have always thought that is because of the situation with the disease. And it may or may not be. . . I do resent that sometimes, and I resent how much she does for him and for his children. . . when we are all together she always thinks my children are trying to do something to the other children or not play fairly or whenever there is a problem that involves my children, it is their fault. She buys more for the other children and spends more money on them. She pays the doctor bill. . . That doesn't really bother me, I didn't make an issue of that. But my children sense a difference in the closeness that she feels with them and she feels with my children. My daughter has said several times that my mother doesn't like her. That she doesn't care about her. I think, that certainly is not true. But I think it is just because she is such a part of my brother's life and such a part of his family's life. To the point it is almost not natural to the amount of time that they spend together. . . it is almost like she is consumed with my brother and his family, particularly the younger girl. . . It may all be transferred, she may have transferred all her protective feelings from J now to his daughter. She is as close to her as she was to J.

Some participants reported feeling that their relationship with their mother has changed because of the empathy they feel for her.

> I think this situation with J made me see her more as a human being than as a parent. She will always be my mom but it made me relate to her more as a person instead of a mom. Because as a mom I looked at her and I just thought, I always thought, you are so stupid, you are killing yourself here. But then as a person I looked at her and thought well if it was my baby and I felt that much obligation, or whatever, or that much heartache over it myself, watching him self destruct, I don't know if I would manage it any differently. . . So it has always made us, I guess it has made us, not necessarily closer as a mother and daughter but more as

> friends. You know even if I don't agree with how she handles him, I can still empathize at the same time. (Amy)

Many participants felt that the experience of having a chronically ill sibling affected their relationship with that sibling. Three issues emerged from the participants' description that directly or indirectly transformed their relationship with their chronically ill sibling, creating a change in how the participants relate to their ill sibling. These three issues include: 1) Rôle reversal, 2) Endearment vs rift, and 3) Failure of diabetic sibling to reach potential.

Participants perceived that because of their sibling's chronic illness there was a change in roles and a change in how they felt about that sibling. Examples of these two changes are given below:

Role reversal: Frequently participants described changes in their roles in the family. Many described becoming the caretaker of their sibling even when the ill sibling was chronologically older or previously was the participant's caretaker. The participant often readily accepted a caretaker role of their sibling regardless of birth order. For example, two participants become the caretaker for their older sister:

> When we feel as though she can't, me and mama take over. Because my mama gets worried. If she is home by herself she will call me or mom and we'll go out there. It is something that we have done for years and years. (Joyce)

> Through the week if I go over there in the mornings I still fix her shot for her if she is in a hurry or something, fix her toast for her, or get her some orange juice or whatever. It is just habit. It has just become habit. (Jean)

Jean also takes on the mother surrogate role and becomes concerned when her sister participates in risk taking behaviors, such as drinking alcohol. She perceives her sister as not knowing when to stop because of her desire to be "normal". Jean feels the responsibility of her sister's behavior. She explains why she refrained from drinking any alcohol at her engagement party, knowing her diabetic sibling was at the party:

> You just want to smack her hand and say 'don't do that.' . . . I knew somebody had to keep her from getting out of control. . .just somebody to look after her and make sure she is not going to be falling on the floor. Just making sure, I don't want to have to take her to the hospital. I definitely don't know what to do with her if she is drunk and her blood sugar is going haywire. . . I had to get mad at her and just say, 'no, you can't have anymore.' Just like a mother would tell a daughter. You just have to say no. I think she had run out of money or something and I had money and I said 'no I am not going to give you any money for a drink, I'll get you something to eat, I am not buying you something to drink.' She was mad at me. . . I was so mad at her by then that I didn't care if she got mad at me. It was something I knew that I had to do.

Carol believes that her sister is still in her childhood and that the roles between them have reversed:

> If I had to give a description of her, she is still in childhood. I think being a diabetic she missed some of her childhood. Literally speaking she didn't, but in her point of view I think she did. . . I say that because to me she is still a child. I am more the older sister. I am younger than her but I am still the older sister. I still have to take care of her I guess you would say. I still, when we go places together, make sure she gets her shots. . . I would just think

> it is time to eat, do we need to eat. You're acting a little funny M, what do you need? I watch after her. . . It drives me crazy. It really drives me crazy. I think she is more irresponsible, I guess. To me I shouldn't. . . even have to monitor stuff like that.

Endearment vs rift: For some participants the illness was seen as bringing them closer; for others it was seen as causing a greater rift in their relationship. The following comments present this theme:

> I think I pay more attention to that relationship. I told her things that I really think and how I feel about things. Maybe because. . . I want her to know how I feel about her. I want her to know that I miss her. . . As far as my relationship with her I quit thinking about myself so much and thought more about her. (Karen)

> We lived in a trailer together. It was on the home land. We had been talking back and forth and she got up, I was in my room and she was in hers and we were still talking back and forth and I saw her go in the kitchen and all of a sudden I heard this big crash and the cat come running in the hall. I could not figure out what was wrong. I said M are you alright and nothing was ever said. I went in there and she was laying in the floor. My first response, all I can remember was sugar. I am supposed to get her sugar and I just took the canister, opened it up and poured it down her throat. Which that likely killed her. But I remember that real, real well. That was when I finally, she and I were real close but yet she was real distance. . . I think all and all it made us a lot closer. She and I understand each other a lot more than the other family, rest of my sisters. (Carol)

> She is a year younger than me and she is one of my best friends. . .We talk to each other, we are not afraid to talk to each other if we are down or if we have problems. She probably talks to me as much as anybody, other than my mother. We share a lot of ups and downs. (Tyler)

> It has amplified those differences enormously. We have always had those differences. He was always type B and I was always type A. As the first sibling I acted the role perfectly. But it has made it enormous, it has made the differences even more, more huge. . . I am not

> going to deal with him. He is not going to be my friend. We are never going to be compatible, I don't like him. (Amy)

> Those T.V. programs come before any contact with you. She would rather listen to those than talk to you. And when you are down there she has very little interchange with you. I think it is primarily to the fact that there is nothing for her to interchange about. She has no activity in her life. She has nothing to talk to you about. . . . If you go down there, like I said she sleeps every afternoon from 2 to 5 pm, you know if you go over at those times she will not be up. So when I do go there I feel guilty when I can't spend much time and I know she'll be in bed at that time. But it is still that she knows you are coming, but she does not make an effort to try and stay up. She has to go to bed for those hours. . . I think she feels cheated because of the fact that you have so much going on and she has nothing. So the way for her to survive and keep her motivation going or her self esteem going is to shut down completely, I got my life and that is all I need. And I don't have to interchange. I don't have to listen to yours. I don't have to become involved in yours. (Sarah)

Failure of diabetic sibling to reach potential

Because of the chronicity of their sibling's illness some participants perceived that the illness prevented their diabetic sibling from reaching his or her potential. They believe that their ill sibling has never developed an independent life because of the illness, and consequently, is too dependent on his or her parents. This perception indirectly changes the sibling relationship. The following statements express this perception:

> J (age 22) has never been able to leave home and succeed or be independent or be able to manage an apartment and a job, money, food, and clothing. All those kinds of things. Anytime he has lived away from home he has ended up back. . . I definitely think he is stuck. When you talk to him he doesn't talk like a 23 year old. He talks like a 17 or 18 year old. I think

that is where he is. Developmentally, I think that is where he is. (Amy)

I don't think he grew up and accepted responsibility quite as quickly as maybe he would have if he hadn't had this condition. Because I think more has been done for him. My brother and I both maybe babied him more than we should have and it might have caused him not to be as independent and stand on his own two feet as quickly as he would have. . .it just seems like my brother can't make a decision about anything without calling my mom first, checking it out with her and seeing what she thinks. . . Even to this day I have felt she is more protective of him. She has a closer relationship in a lot of ways with him than she does with my older brother and me. . . But I know as a parent now if I had a child who was diabetic it would probably be harder to let them cut those apron strings and pull away as much as it would be for a child who did not have a medical problem like that. (Ellen)

One thing that really drives me crazy that she does is that she gives him his injection. It just drives me crazy. Oh, it drives me crazy. She doesn't draw it up, he draws it up. But then he never wants to give himself an injection. I just think that is so babyish. It just drives me crazy. . . I just think it is so childish. Just give it to yourself. You know he does do it when she is not at home. When she is there, he hands it to her and she does it. (Amy)

All these years way up to age 38 she has still continued to be there for him. And the relationship really hasn't changed that much from when he was a little boy, the way I see it. And I feel sorry for both of them because I think they would both be happier if the relationship had grown a little more past the point of where he is. So I don't think she respects him as a man. I think she still looks at him as a child and I think he feels that mother still looks at him as a child. . . I feel that J would be happy within himself if he could have somehow cut away, you know, like I said, grown up more standing on his two feet more. (Ellen)

She (diabetic sibling) has had to go back and forth to my mother. . . she had no choice most of the time. . . she has not really had an independent life as an adult to the point that it lasted long enough to make, like most people have. It all has been attributed to the problem she has had, her sickness, her diabetes. . . I see S as a child. She can't be an adult. . . my mother

> does give in to her. . . I think that she can carry anything to an extreme and cause more harm than good. Giving S a haven to come home to all the time regardless of what it did to her situation and not making her stay out there and fight for herself or allowing her to become a hermit and a debilitating adult. I think it was the easiest way to deal with the situation so my mother allowed it to happen. She could have fought against her and she could have fought to make her more motivated to better herself or to get better. Even with her debilitating problem to be more of a person, have more of a life. . . Mother lets her have her way a lot, just like you would a child, a young child who was chronically ill. (Sarah)

Worried/Responsibility Without Power

A second theme participants described during this period concerned being worried and responsible for their diabetic sibling, but often perceiving themselves as having little power over the situation. For most participants concerns relating to their diabetic sibling increased as adults. For one participant maturity brings a greater awareness of the seriousness of the illness:

> When she was diagnosed, I don't think I realized the consequences of all that could happen. It was that she was sick and she had to take shots and she had to eat special foods. But at the teenage years I didn't realize all the consequences that could happen that I did as we grew older and I saw the illness developing. (Beth)

Participants believed that they began to worry more about their diabetic sibling when the sibling moved out of their parents' home.

> I knew when she was home she always had someone to look after her. When you leave that nest you have to worry. (Joyce)

> The fears came whenever she went out and started living on her own. You know, no one there at night. Or when

> she went on vacation. Do they know you are a diabetic? Do you have enough insulin? (Beth)

The majority of participants expressed concerns about their sibling's future, the "what ifs". Most of the concerns regarding the "what ifs" of their siblings were concerns for their future health and early death. Many siblings expressed worry about their ill sibling. Examples include the following:

> Is she going to be okay? Will she eat correctly? What if she binges and gives herself too much insulin? . . So these are little fears that nag at your mind. The what ifs, I guess. That's always there. . . I think any change in her life, from high school to college, from college to the work force, it was all a whole new set of what ifs. . . So here again this fear, a bad cut on the foot, bleeding starting up in the eyes, so now you are always well how is your blood pressure. What is your cholesterol count? Is this blood pressure medicine putting stress on your kidneys? You know, now it is also the fear of the medications, the fear of her body deteriorating. (Beth)

> It just worries me about her future. . . My greatest fear for her I guess would be acceptance, meaning her accepting that she may not be able to have children in the future or accepting a lot of things that she will not be able to do because of her diabetes. Because like I have said she is a very emotional. . . not having any children, not having a quote normal life. . . I can just see the consequences she would have to pay to have a child. Dying, kidney failure or whatever. (Tom)

> It seems like she has to get new glasses every year since her eyes get a little worse every year. . .You know you hear all these things about diabetes going wrong with their feet, their circulation, their eyes, their kidneys, everything and I guess we worry about her not taking care of herself. Because we don't want things like that to go wrong with her. . . I guess maybe it is the not knowing that makes you worried. . . It seems like that little things happen at different times over the years, something else almost every year. Maybe it is not a major problems, but it is something wrong. It is like what is she going to find out this

> time. . . Just don't want anything major to be wrong because you don't want to have to be anymore worried than you already are. (Jean)

> I worry about her all the time. . .You hope and pray for her that she is going to take care of herself. . . With her job she goes out of town now, and she is out for three or four days at a time, and she comes back in and she is by herself a lot at night. That kind of worries you. . . I worry about her on those trips now because they are so far away. And she don't have anything on her person, a bracelet or anything like that, stating that she is a diabetic or anything like that. I worry about. . .times she went into shock. It worries you. You worry about them, well I do a lot of praying anyway, and you worry about them all the time and you pray for them. Especially those times that she can be taken from you at anytime. (Tyler)

Karen is concerned even when her diabetic sister catches a cold:

> There is always the worry that she is going to develop some kind of problem. . . I hate it when she even just catches a cold. I am always afraid it is going to get a lot worse. That she is going to develop something really bad.

Adding to participants' concerns and responsibilities for their ill sibling, is the painful awareness that they will outlive their ill sibling. Beth's ill sibling tells her "you know you will outlive me and you know that my life expectancy is 15 years or more less than what yours is. So you may as well accept that fact." She reacts to that statement:

> She should not have told me, now I am here thinking "oh no." We are getting some age on us. I am going at it with a negative rather than a positive. . . Unless I get cancer or something. With a normal life span I'll outlive her.

Jean is also very aware of her sister's reduced life span:

> I know that diabetics don't have as long a life span as me or you. . . me and my dad have talked about it before when she doesn't do good with her diabetes, times when she does complain of something hurting or, I guess that is when we think about it. We worry about her then.

Sarah also talks about her sibling's death:

> It has been real frustrating knowing that she is going to deteriorate and she is going to die soon. . .Unless the Lord takes me first, as far as physical reasons.

The idea of the diabetic sibling dying is ever-present on the minds of participants. Beth discusses the responsibility her ill sibling has placed on her to make sure she does not stay in a coma:

> She told me many years ago, I guess we were in our 30's, she said that if I ever go in a coma, this was before the living will and all, if I am ever to go in a coma then you are to make sure that I don't just lay there. You are to unplug the machines. I told her that I can't do that, that is not legal. Then she told me to carry in a bottle of insulin, since I have insulin anyway, then they won't know the difference. But you are to make sure I don't stay in a coma. I said okay. Since then she has told K (participant's daughter) that down the line your mother will not made sure that I don't stay in a coma. You are to make sure that I just don't lay there for three months or whatever. K said 'okay.' She believed K but she didn't believe me. And she told her the same thing. . . And this has been for years that she has told me that I was to do this.

Two specific concerns the participants had regarding their diabetic siblings were the ability of individuals, who were not members of the family of origin, to properly care for the diabetic sibling and the diabetic sibling's risk taking behaviors. Examples of such concerns include the following:

> I know she went to California with a friend but that was such an issue. Not because of the money or the time but her just being away from people who knew how to deal with a diabetic, if she was to go into an insulin shock. . . Because you want people around her who know what can happen and recognize what is happening. Because that is another issue being able to recognize it. (Beth)

> Is his wife preparing his meals the way they should be prepared and that type of thing? I am sure that she doesn't always and they eat the fast food and things like that, which he never did when he was living at home. (Ellen)

> I was pretty calm, I had seen this before but she had never seen this before and she was freaking out. . . His wife is smaller than he is. He is not all that big. He is not nearly as big as I am. But still yet somebody in that state of mind could not be handled by somebody her size. (Eric)

> They all knew that A was a diabetic but I am sure that they don't think about it like I do. I know that they were drinking that night. . . It is not in my hands when things like that happen so you just have to wait and see. . . It's just that at the time you get worried for her. You are thankful that she is alright afterwards. (Jean)

> He is real self-destructive. He drinks a lot, parties a lot. So what would end up happening would be that he would go on these drinking binges with his buddies, and would either not come home one night or he would come home at two o'clock in the morning. That does wonderful things for your blood sugar when you drink like that. You don't have any insulin. Either he would come home acting off the wall. He would come home in the middle of the night and he would be really sick. He would be vomiting. He would be so drunk that there was no dealing with him. It was just get him into bed. But then the next day he would still be, his blood sugars would be up and down, all over or stay real high. He was hard to arouse. (Amy)

Participants perceived that they and/or their parents manage their concerns and fears by becoming over-vigilant of the adult ill sibling. Some participants perceive that the over-vigilance of the diabetic sibling, the protective

shield, initiated in childhood, continues into adulthood.

> Mother never broke off that protective shield that she always had woven around him wherever he went. (Ellen)

> My mother calls her every night to make sure she is okay, because she lives by herself . For that reason, if for nothing else, just to make sure she is okay. (Tyler)

Carol lived with her sister for awhile and during that time her mother would bring groceries to them:

> When we lived together. . . she still made sure we. . . always had milk, always had peanut butter, always had crackers, things like that. She checked on us for things like that.

The following excerpts illustrate the participants' strong concern for their ill adult sibling:

> She is now by herself again, so I have this need to make contact with her everyday. And if she doesn't call me, I call her. . . If I can't get her I start going, I'll give her until I think she should be home, so now she knows how paranoid I am so she will say, 'I am going out to eat with so and so, don't worry.' That sort of thing. . . So from the time of the first insulin shock. . . and with the death of my parents, it has been a gradual you are the one who is going to have to make sure that she is okay. And you are going to have to be the one to make sure she doesn't lay in her house dead and no one know that she is there. . . So it has become this fear that she will go into shock, not be able to catch it, her blood sugar level will go zero, and she will just lay there in a coma. So right now that is the big fear. We all live in fear that something can happen. (Beth)

> I have to keep an eye on her still. She doesn't know it but we still look after her from a distance. I think the rest of them do too. I think they keep good track of her too whether they would talk about it or not. . . I talk to N and I talk to mother and talk to her. We all compare notes. . . how J is doing and stuff like that. (Mark)

> I am over protective still to this day with her. She gets frustrated with me. I make her check her blood three or four times if I think she is low. . . I know

> to look for the glossy eyes, weaving back and forth and things like that. She'll do some of that just, I don't know if it is a habit or what but it scares me and I'll make her check her blood and she'll sit there and argue with me, I'M Fine", but I'll still make her check it, she'll get very frustrated with me. Which I guess I would too if I had to prick my fingers that many times a day. (Tom)

> We just have to keep tabs on him. And his wife travels a lot. . . and he is there by himself a lot. . . We just have to do the telephone duty. Call in the morning to make sure he gets up. Call at night to make sure he is awake. But he has a bad habit. Sometimes he's got to go to work early and we call about 7:30 to make sure he is up and sometimes he has to leave at 5:30 and he'll forget to tell anybody and we can't find him. And they won't be able to find him at work because he'll be in a meeting somewhere. But so far when he has been there by himself he hasn't had any real problems, fortunately. (Eric)

> I still worry about her and contact her, and talk to her quite a bit on the phone. (Tyler)

Having learned to be vigilant for their diabetic sibling, some participants were not even aware how much their protective behaviors had become a part of their daily routine. Consider the following passage:

> I love my sister so I don't want anything to happen to her. I don't want to feel, I don't want to have to feel that I have to protect her, but you do. You just do anyway. I guess maybe after all these years maybe it is just instinct to worry about her and to watch what she is eating, even when she is not. . .maybe before this interview maybe I, maybe everything I was thinking of, I thought was normal. To me I have never looked at it this way. I never. . .I guess maybe I never realized how much I looked out for her, how much I worried about her. I guess it was, I don't want to say everyday because it was not everyday but it just seemed normal. Even now it just seems normal to wonder if she is doing the right thing for herself. Even through the week, if I go over there in the mornings, I still fix her shot for her if she is in a hurry or something, fix her toast for her, or get her some orange juice or whatever. It is just habit. It has just become habit. (Jean)

Participants focused on their concerns for their diabetic sibling, but also emerging from the protocols was a number of concerns for themselves. These included the possibility of having to physically care for the diabetic sibling, a concern about acquiring the disease themselves and a fear that their children will become diabetics. These themes are illustrated below:

> If something happens I feel like I am all that would look after her or take care of her. So now I said we can fix an apartment in the basement or we can build you a house at the farm or somewhere close. So, I think, I also try to give her security in if she wants to come back home she can. And she has a place to go if her life becomes to the point that she needs extra help. . . I just feel more responsible. I still knew all this stuff, but I think I look at myself as more of the caretaker now. Whereas she (mother) was before. (Beth)

> I think they both fear the other one going really bad. My mother is 65 years old and in all eventuality she could continue until she is 80 . . But she is going to deteriorate just by age alone. . . It is going to be a very difficult situation. She doesn't want to be placed in a nursing home. And even if she was what would you do with S. . . I can't dream of putting my mother in a nursing home anymore than she wants to go. But at the same time I couldn't take them both in. So even though this has been a life long situation the end will be harder unless it is a sudden one. . . The worry that goes with that. . . So it is going to be hard to take care of them. So even though the end is getting near for my mother age wise, as far as being able to physically take care of S and S's problems are going to be more and more serious as she ages too. You got a very difficult situation ahead. (Sarah)

> When something like that happens (hypoglycemic reaction) it is like I'll do what I can do to take better care of myself because mom is always saying you could get it, you could get it. I start eating better, exercising more. . . when something like that happens it's like I always feel that it is going to happen to me. Over the years, or in twenty years, mom has me convinced, well she doesn't have me convinced, but I do

> realize that I could get it. When something like that happens I try to take better care of myself because I don't ever want to give myself a shot. . . I was really afraid of having a baby that big that they would be a diabetic from birth and it really scared me. When C (participant's child) was born her blood sugar was, I think it was a little low, and it just really scared me that she was going to be diabetic from birth. . . I would be afraid that they would feel left out or different. I guess a parent can only do just so much to let them know that they are just as normal as any other child. I worry about how they would feel, more so than what I would feel. How they would react to a life style like that. (Fran)

> I am more or less wondering if it is going to happen to one of my children. That is the only real question in my mind, which now I think there is a lot more technology and all and it doesn't scare me so bad anymore. I think the cost is more scary part than anything else to me. I know now that she has lived with it and goes on with a normal schedule. That is the only thing that really scares me about it. Is being able to afford a child. If I do have a child who is a diabetic, will I be able to afford it? (Carol)

Although experiencing many concerns, participants often perceived themselves as powerless in the situation, or in their ability to effect change. The following excerpts illustrate such feelings of powerlessness:

> It was devastating just to see her lying there, knowing you can't do, we couldn't help her hardly. Just besides putting the sugar on her. (Tom)

> All I know what to do is give her candy, give her orange juice, you know. So I guess that is all I know how to do, I can't do anything else, besides call someone to get help. . . I am just scared, just scared to death that she is going to fall over and there is nothing you can do about it. That's your sister and that makes it 10 times scarier. (Jean)

> She is 26, so you can't say, 'A you better eat this and that.'. . You want to take care of her but you can't, you just have to let her do her own thing, because that is, she might, if you say you can't eat that and here I am eating it, that is not very nice. . . you sort of have to stand by and watch anyway. . . You know there

> wasn't anything I really could do for her. You just worried, you think about how it is going to affect her in the long run. (Jean)
>
> She is going to do things her way or no way a lot of time. . .I feel like my sister is stubborn and I don't know if you call it helplessness or anything like that. You just feel like you would like to help somebody, and they don't want to hear about it. It is just a feeling of helplessness, it is like you want to help them, and you can't, because they don't want to hear it. (Tyler)

Frustration and anger were common emotions felt by the participants as a result of their powerlessness in controlling their sibling's behaviors. The following are examples of these emotions:

> Well a diabetic like C, which she has had diabetes since she was 4, knows that if she takes her shot she needs to eat. . . And she doesn't want to eat. She has a really big problem about weight gain. She is a big girl but she has had a bad problem about weight gain. It is the constant, it is the ignorance. She has had it since she was 4, she should know by now. She has to eat. . . she is not on a diet, she eats basically what she wants to. She drinks regular cokes one after another, one after another. She just does not take care of herself. (Meg)
>
> Mostly I always felt really angry at him. Because I don't look at it as something, I don't look at diabetes as something you would even treat as terminal. He kind of acts like this is this terminal thing. . . It's just "why are you such a baby?" I always felt "why do you feel sorry for yourself?" . . .you choose to wallow in your self pity. That is the way I always felt. . . What makes me angry about this is that we all have to suffer because he chooses to have his life style. I went to school with plenty of kids who drank all the time. I had friends that drank all the time and partied all the time, stayed out late, were reckless or whatever. I went to school with a lot of kids like that but it, none of my friends had diabetes or none of my friends had a chronic illness. So it wasn't that, it did not involve their families or whatever. (Amy)

Some participants also felt that their diabetic sibling was powerless within the situation. The following statements express this theme:

> She has taken care of herself, but it just hasn't helped much as far as her life is concerned. . . she did everything she could do in my eyes to maintain the illness or try to keep it under control. She has always kept her doctor's appointments. She has always kept up with all the things they told her to do. . . I don't think she ever did anything outlandish enough that it would hinder the problem or made it any worse than it was already. So I think she did all she could do. And she still does. (Sarah)

> Even though he is taking the insulin like he should and eating right, he still went into a reaction. . . It's like the least littlest thing you do wrong could cause a bad accident, or an insulin reaction. (Fran)

The immense power of emotions expressed in many of the interviews regarding the concern they had for their sibling indicated that these concerns were a central aspect of the participants' lives.

Empathy/ Sadness/ Guilt

The third major theme concerned the participants' feelings of empathy, sadness, and guilt. Empathetic feelings were expressed in many protocols. Some participants expressed empathetic feelings toward their mother. The following passage illustrates this theme:

> It bothers me that my mother worries about it. And I worry about my mother worrying about it too. It worries me when P is depressed. It is stressful on my mother. That part of it worries me too, I worry about my mother and the stress on her. . . I think it is hard on her. She has always waited up for my sister until she got a call from her. Sometimes my sister won't call her at night and she would have to call her and stuff like that. It just bothers me that she is stressed out about it too. My sister, a few times has

> not called her at night, and has just come home, and gone to bed, and she would be okay. . . It would bother her for awhile, practically all night. . . It bothers me because I know it is stressful on my mother. (Tyler)

Several participants expressed empathy toward their diabetic sibling for having acquired the illness. Participants also were very conscious of their own health, almost expressing a relief that they had not acquired the disease. Some participants perceived that their diabetic sibling was handling the illness much better than they thought they could manage the illness.

> I didn't get it, what a bummer he has to get it. (Amy)

> I am real sorry it had to happen to her, I wouldn't want anyone to have the problem of that disease especially the attitude towards shots that I have. I hate to take shots even though I am 43 years old, weigh 250 pounds, you wouldn't think a man this old, this tall, this heavy would worry about anything like that. But I just hate to take a shot. That was the one thing I thought if I had, if I personally had diabetes I don't know if I could deal with it like she has or not. I have been real proud of the way she did it, I was really sorry that she had to have it, but she has dealt with it a whole lot better than I would have. (Mark)

> I am terrified of needles. I have been since birth, I just can't stand needles. I am very proud of her that she can overcome that and just give herself a shot wherever and whenever needed. . . .I told her that I don't know how you do that, but I guess when you have to do something to survive it makes a big difference. (Tom)

> I think I am just glad I don't have to give them to myself. I don't much care for needles. . . I wouldn't want to have to go through something like that everyday. It does not look like something that would be enjoyable. He has had to move around quite a bit where he gives them because it does tend to atrophy the muscles in certain areas. (Eric)

Participants were aware that they are healthier than their ill sibling. One participant clearly articulates the

guilt this produces. Examples of this theme include the following:

> I'm fine, I get up, go hop in the shower, go to work or whatever. She has to stop and take time and take her shots and sometimes make sure she has the right foods to eat. She has to make sure she has got good shoes, make sure she got good glasses. . . I don't have to worry about keeping candy in my purse or orange juice in the refrigerator or stuff like that. I don't have to think ahead for certain situations which she does. . . I feel sad for her, knowing that she is more susceptible to having more things wrong with her than me. . . she got a heart murmur, and like I said her eyes, her feet. I don't have those things wrong with me. (Jean)

> I am aware that I am physically healthier. I am physically stronger. I don't have the threat of blindness or amputation. I can do more than she. I don't have to let my life be controlled by when I eat. . . So I am more aware that I am not being controlled by a disease like she is. (Beth)

> She already has had more sickness and pain than most people have all their life. I never had to deal with that kind of pain. . . I feel guilty. I have a life of my own. And being happy. . . here I am going through this program (higher education) in this late point in my life knowing that she was, and still is very smart. And she can't do that. She will never be able to do that. . . she is always the one with the health problems. I wouldn't know what being sick was in comparison to her. I wouldn't have any idea. . . I always feel guilty having good health and happiness and knowing what she went through for me. Just what life has handed her. She just got it all. It could have been more evenly distributed. She has always taken it and gone right on. . . I don't feel like I have ever been there enough for her. I have always felt like I have had a life separate from hers, which is the way it is supposed to be, but in regard to her needing someone else, I feel like I have never been there and been able to be there as much for her as I would have liked to have been. . . I regret not giving her the sacrifices she gave me when she took care of us. (Sarah)

Occasionally the guilt a participant was feeling was reinforced by the perception of how their diabetic sibling

felt or behaved towards them. One participant feels that her diabetic sibling resents her ability to be independent and care for herself.

> And now I think she kind of resents that I am my own kind of person. That I can take care of myself. . . She is always telling me that I wasn't dealing with as much. (Beth)

Another participant noted that her sister wants her to feel guilty and resents her health:

> I think a lot of times she wants you to feel guilty. I really do. It's like sometimes she uses her illness as an excuse, as an excuse. . . like one day I was sick or something, she'll say, 'I am a diabetic and I am sick, but I still work everyday.' As long as I am taking care of her kid, my kid, my mama, my daddy, my husband, I work every day too. I take care of her. It is like sometimes she just wants to make you feel guilty. She makes you feel guilty. (Meg)

Some participants dealt with being healthier than their diabetic sibling by normalizing that sibling. Consider the following passages:

> She has it down now that if she wants to eat a candy bar she knows how much insulin to give herself. It is not a problem. She has gotten to where she lives a pretty normal life. If she wants to go out somewhere and have a beer, a drink or something, she knows how much insulin to give herself in addition to what she would ordinarily get. She deals with it real, real well and she stays in shape, walks a lot, exercises a lot. (Mark)

> I don't think of her as a diabetic. She is just normal. She can eat pretty much what everything we do, just in moderation. (Jean)

> She is probably in better physical shape than I am, because she exercises three to four days a week. She works out at a health spa. She does a lot of running and weight lifting. She is actually in better shape than I am. . . diabetics are not that much abnormal, other than having to watch their sugar and their blood levels. (Tyler)

> As it turned out he has had a normal life. And he has two children. He is on two injections a day. He is a severe diabetic, he is not a brittle diabetic in that his can be controlled with the medication and he has lived a normal life. (Ellen)

> I always try, I don't know, I don't ever make him feel like he's a diabetic. I don't ever, ever press that issue. . . Every time we are together I'll fix something sweet and I'll ask him if he wants to try it and I don't think anything about it. If he tells me no I don't think oh yeah, he is a diabetic. That don't even cross my mind at all, it is oh well. I really don't think anything about it at all now. A lot of times I have to remind myself that he is a diabetic, but yet I am not going to treat him any differently or give him special treatment because of that. I give him special treatment all the time but it is never because he is a diabetic. But sometimes I just have to say, oh yeah, he is a diabetic. (Fran)

Burdened

The fourth theme concerned how participants perceived their sibling's illness was affecting their daily lives. Participants experienced a number of burdens resulting from their sibling's illness. They described sacrificing their own time, health, families, and careers to care for their adult diabetic sibling. When Joyce's adult diabetic sibling is in the hospital she makes sacrifices with her own family to be in the hospital with her:

> I usually stay down there with her for more than 12 hours. . . I think I have worried about her more than my own kids.

Tyler becomes depressed and worries a lot when his diabetic sibling talks of suicide:

> You are kind of depressed with her too. When she is depressed it kind of wears off on you. You try to think about the positive things. . . I tell her that she has plenty of life to look forward to, people like me and my mother and dad. . . need you to be around.

> You got to come and really be strong with her. You got to give her a feeling of hope. Be positive. . . It makes you more scared than anything. You don't want to lose her. It is scary. You tell her that we need her. I would have an empty place in me if she left. Try to tell her that you need her. That if she left you, there would be a place that couldn't be filled. You tell her all the people that need her and depend on her. . . Just got to try to block out feeling depressed yourself when she feels depressed. That is the way you feel, it just pulls you down. You just got to say, 'I got to get over this,' and try to tell her everything she got going for her. How we all love her and depend on her for certain things. You just block it out and don't say that you are feeling down, and just go on from there. It wears on you. . . you can't go to sleep. . . Be thinking about her at work. . . It is kind of taxing on your brain, because you are thinking about her, you are trying to do your job, and you are thinking about something like that. It is not a happy thought and it is just tiring. . .You are restless.

Meg is frustrated about caring for her sister and having to sacrifice the needs of her daughter.

> I am still running back and forth down her house with her running into hypoglycemia. Because every time that happens her husband automatically calls me. . . He calls me and has me come down there because he asks me what to do. I say just call an ambulance. And he says come down here and we will call. So I go down there and I check on her and sometimes I try to give her a little orange juice and sugar. If she is too far gone I just go and call an ambulance for her. I think it is because he is so torn up and plus with the baby. . . He is so torn up himself because he is her main caretaker now. I guess he thinks 'If something happens to her, I will be by myself with this baby.'. . it frustrates me because the majority of time when this happens it is usually in the mornings and I have to get my little girl to school too. I have to take her, she don't have a bus or anything like that. . . I have to make my little girl be late for school because I am trying to take care of her. It really just makes me angry because it just puts me in a rush when all you have to do is just eat. I can't understand that.

Meg states that she has put her career on hold for her sister:

> She works everyday and I've pretty much put my career on hold so I can help her and stay home and watch her little boy. She has a lot of stress if she doesn't have anybody to watch him. She worries about her job. So I have just given up work and put my life on hold until I can get him, at least until he is school age.

Meg feels that all this caring for her diabetic sibling has had a toll on her health:

> It is stressful. . . It is really stressful on a person. I am 26. I am on blood pressure medicine, nerve medicine and that is quite a bit for a 26 year old.

Often participants perceived the burdens of the illness as having a direct impact on their spouses and/or children. Participants spoke of various ways in which their families became involved with the care of the diabetic sibling. Examples of family involvement include the following:

> My husband got dragged into it. He had to go and help move J out of the apartment because he hadn't been paying his rent so it was going to be my parents paying the rent or him going to the homeless shelter. So my parents had to go clean up the apartment, clean up J because of course he was an absolute wreck and my husband, because I was at work or something, had to go move furniture and clean up that apartment. I was so mad because we had always said this was not going to work. You know he is a baby, he can't do this. And my husband spent his Saturday cleaning carpet and cleaning the walls. (Amy)

> My daughters realize how sick she can be because when she is home by herself they will go out there and stay with her. They take care. . . afraid that something will happen. They understand. . . she will call when she is afraid to stay by herself and they will go out there, they understand that someone has to stay out there. (Joyce)

One participant spoke about the impact her sister's hypoglycemic reactions have on her children:

> It was so dramatic for my girls to see her that way. So something was happening I can't remember what, I was sick or something, and my daughter R said, 'mom are you running a low blood sugar?' So now they associate anything out of the ordinary with our health with low blood sugar. But these little episodes are really traumatic and frightful. (Beth)

Some participants perceived that the burdens of the illness have precipitated negative outcomes in either the diabetic sibling and/or in themselves. For example, Sarah blames the illness for her sister's failed marriages.

> Illness plays a huge role in relationships, especially if the partner is unable to take care of that responsibility. Her first two husbands and her third husband, even though he was a responsible person, were not the kind of people that could handle that kind of responsibility. So she has never had a lasting relationship. She has never enjoyed the security of that. She has never enjoyed the fulfillment of having a family as a result of losing the children. She has never had the experience of being able to do in life of let's just go here or let's do this or that. She has never had the fulfillment of life, I don't think. . . Everything she has ever had has turned to pot. It has always been linked to her being ill. In one fashion or another it has always been linked to that.

Carol attempts to associate her sister's lack of courtesy with the illness:

> She doesn't have the common courtesy. Who knows if that is related.

One participant perceives herself being overweight as resulting from her sister's illness:

> I think her illness might be. . . the reason I am so big because during Halloween and all that she had to give all her candy to me. She could not eat it. The same goes for no sweets. Mother always made sure she stayed on her diet when she was young. . . They always pushed her stuff off on me. That pretty much did a lot of bad things for my eating habits. (Meg)

<u>Can't Talk About Feelings</u>

The fifth theme concerns the participants' belief that they cannot truly express what they are feeling to their ill sibling or other family members. Participants articulated various reasons for suppressing their true feelings. Joyce feels she needs to hide her feelings from her sibling by putting on her happy face because:

> She has enough problems, she does not need to be depressed.

Communication for Ellen with her mother and brother has become difficult. She does not want to hurt them because they both run the risk of a serious illness:

> I am just very careful now as far as what I say because I don't want to upset her. It is not worth it. . . the one time I tried to talk to her about it sometime back, her blood pressure shot way up because she got so upset. She gets real defensive. She says she is 'always trying to be fair and she is always trying to treat all my children equally but no matter what I do, someone is upset.' Just that kind of thing. She just started having a pity party. So I made up my mind right then and I was so scared because her blood pressure went up. . . gosh it is not worth it, you know, to bring up anything that is going to upset her. Same thing with J, I would not bring up anything with J because. . . I think, well he's treated this way because of his illness and I try to not let it bother me because at any time he could become severely ill. And I wouldn't want to do anything to damage our relationship or say anything that would hurt him in anyway. Because at anytime, I feel he is probably pretty fragile and he could suffer a severe illness at anytime. . . I would never want to upset him or talk to him about any of these things that concerns me because it wouldn't be worth it to me, because then if he would get sick I wouldn't want to have to always remember that we had a knock down, drag out discussion about what was bothering me.

Jean also believes that she must suppress her "true feelings". She feels concern and sadness about her sister's future but she must suppress such feelings:

> I can't really talk about it because she is going to think I am feeling pity for her. She doesn't want anybody to feel bad for her, because she wants to be thought of just like you and me. I guess I try to make her feel normal.

Tyler often censors what he would like to say to his sister because of a fear of making her angry:

> I tried to be to a point but I couldn't because she would get mad at me. I try to treat her as normal as I can. You worry about her and stuff and you try to say something to her, but she would get mad at me a lot of times. It happened to me more than once.

Meg cannot express her true feelings because of the fear of losing her relationship with her sister and her sister's threats of suicide:

> With me and C it is not that I can't express my anger, but I don't want to. Because as children, and even really as adults, we were so close, and I don't want anything to destroy that. I think to myself that she don't care. That she is just ignorant about the whole situation. And that she has no respect for nobody else and what they may feel. But yet like I said I let it go at that because I don't want to cause a break in the bond that we do have. . . the least little thing will set her off. I don't want to do anything that upsets her or anything because of the way she talks now. Like I said if something like that happens or something like that erupts she won't eat.

One participant suppresses her true feeling despite the knowledge that her diabetic sibling would rather she speak her mind:

> She would rather that I speak my mind, be open, give my opinion, say what I want, then to say you are a diabetic so I am going to let you choose. That would

> never openly be said, because she would be so resentful of that. (Beth)

Ellen admits that suppressing her feelings causes a toll on her mental health:

> I have cried. . . it bothers me a lot and it has caused me a lot of tears and a lot of anxiety and a lot of frustration and like I said if I didn't have my husband and friends to discuss it with I would probably just be really, really, more upset and unhappy about it. . . I would probably explode.

The above present themes are not isolated, distinct themes but are interrelated and connected to each other. Each theme influences another. For example, changes in participants' relationships with their mother and ill sibling create feelings of empathy, sadness, and/or guilt. These feelings arouse worry, concern, and responsibility, thus contributing to participants' experiences of burden. Contributing to their burden is their perception of powerlessness. Finally, their inability to talk about their feelings reinforces both their feelings of powerlessness and being burdened.

The present themes are also related and connected to the past themes. Although described differently, the present themes are often the past themes brought forward. For example, participants described relationship changes with their ill sibling beginning in the past and continuing into the present. The wondering of a child is described in adult terms of worry and responsibility. The child's feelings of being jealous and feeling sorry are described in

adult terms of empathy, sadness, and quilt. The scared feelings of a child are described more as adult burdens and worries. The majority of the participants' present worries involve the "what ifs" concerning their ill sibling's health and death. As adults the participants are more acutely aware of their ill sibling's vulnerability to an earlier death. Finally, feeling alone is brought forward by participants' inability to express their feelings.

UNIQUE PARTICIPANT CHARACTERISTICS

It is important to note some of the unique participant characteristics that may have colored the various themes reflected in their descriptions of the experience of living with a chronically ill sibling. Characteristics that will be discussed include: 1) Age of participant at the time of diagnosis, 2) Sibling birth order, 3) Death of one or both parents, and 4) Atypical Family dynamics.

1) Age of Participant at the Time of Diagnosis

Most participants spoke about the experience of living with a chronically ill sibling before and after their sibling's diagnosis. One participant, though, was only a year old when her four year old sister was diagnosed with diabetes. For her, there is no remembrance of life before the diagnosis. Because of her young age she not only feared that her sister might die, but also feared the death of her parents.

> Since P was so sick, I always had a fear of them going away too. . . There is a really big fear that maybe

> that something has happened to them. Maybe they're sick. Maybe they are in the hospital. What are you going to do now? (Meg)

Another participant was 7 years old when her 13 year old sister was diagnosed:

> I think I was too young to realize that she could have a really severe problem. It was just something she did. I didn't question it much. (Karen)

2) Sibling Birth Order

Sibling birth order may also influence the participant's descriptions. For example, Ellen believes that she was less jealous and resentful of her brother's special treatment because she was older than he was.

> It never bothered me that maybe he was babied a little more than I was because I always understood that, probably because I was older. If I had been closer to his age I may have resented that a little bit.

Carol believes her jealously was intensified because she was the youngest sibling.

> Everything was a challenge because she got so much attention, yet I wanted it too. I was no longer the baby. Being the baby in the house I was catered to until that day. Everyone looked out for little Carol until J became a diabetic and then we had to take care of everything.

3) Death of One or Both Parents

Death of one or both parents is also reflected in the descriptions of the participants.

> With the death of my parents, it has been a gradual you are the one who is going to have to make sure that she is okay. And you are going to have to be the one to make sure she doesn't lay in her house dead and no one knows that she is there. . . she always felt like if her life was so stressful or something happened she could always come to my mom's house. . . When my mom died that took away the security of a home to go to. .

> . she and I are the only ones left. . . we are basically the only family that are left. . . So if something happens I feel like I am all that would look after her or take care of her. (Beth)

4) Atypical Family Dynamics

Atypical family dynamics also are reflected in participants' description of the experience of living with a chronically ill sibling. Sarah's 16 year old diabetic sister was often responsible for the care of Sarah and her siblings because of parental neglect and abandonment.

> We lived with her and her husband for well over a year or more, I don't remember exactly how long. Off and on in different places and I was involved with her life continuously because we lived close all the time. . . she took care of us, she was the oldest sister. Unfortunately that falls a lot on older sisters. They get to take care of siblings and she was designated as the mother. She took care of us a lot. Even after she was married she took care of us. So that kept us from being uprooted and going with my mother to places and going here and there and trying to keep up with our lives.

Meg believes that her diabetic sister, who was three years older, provided for her needs during times of family violence:

> Since I was so young she was the one that told me that everything was going to be okay. That caused a closer bond than most of my friends and their sisters have. . . she carried me when I was little and now I take care of her now that I am older.

The above special characteristics have influenced some of the participants' experiences with having a chronically ill sibling. It is impossible to separate the affect of some of these unique circumstances from the experience of having a chronically ill sibling. It also must be noted

that the participants of this study were volunteers, who had a desire to talk about their experiences. This fact may contribute to the uniqueness of the participants, influencing their experience of having a chronically ill sibling.

SUMMARY

The phenomenon of having a chronically ill sibling was described in terms of two interrelated and interdependent periods; the past and the present. The protective shield that was woven around the ill sibling at the time of diagnosis is never removed, even as the ill sibling becomes an adult. Past themes provided the background for the present themes. Many of the themes of the past moved forward to the present, but because of the passage of time, are described differently by participants. The past and the present were both described in terms of significant events and feelings. Significant events included time of diagnosis of the diabetic sibling, medical crisis of the ill sibling, observation of the ill sibling giving him/herself insulin injections, and meal time or dietary restrictions. All participants discussed many emotions surrounding these significant events. In the past, participants were keenly aware of feeling jealous, scared, and alone. As adults these feelings are described as empathy, burdens, worries, responsibilities, and the inability to talk about their feelings.

Participants tended to emphasize the present, rather than dwell on the past, and described how the chronicity of the illness was affecting their adult lives and relationships. Participants expressed feeling many concerns for their diabetic sibling in the present, but were also aware of their frustration and anger regarding their powerlessness. They felt powerless in the progression of the illness and/or in regard to the sibling's risk taking behaviors. Participants described parents and/or themselves presently being vigilant of their diabetic sibling's whereabouts and health behaviors on a day-to-day basis.

Finally, participants described being acutely aware of the severity of the illness. They painfully expressed the reality that they would outlive their ill sibling. As adults, participants see relationships with family members as being very important to nurture and maintain. For many, the importance of taking one day at a time is recognized.

Chapter V

DISCUSSION

The purpose of the study was to understand what it means to grow up with a chronically ill sibling, and what perceptions of this experience are brought into adulthood. Through the process of interview dialogue, participants taught me a great deal, not only about the experience of having grown up with a chronically ill sibling, but also about their current experiences of having a chronically ill adult sibling. The purpose of this chapter is to discuss the results of the study and to compare them with previous studies and theories. Implications for nursing will be discussed and suggestions will be made regarding future research.

When individuals were asked about their experience of having a chronically ill sibling, their discussion included issues concerning two interrelated and interdependent periods: the past, and the present. In examining the major themes described by participants in the past and present, it was found that three threads permeated both periods: feelings, relationships, and coping patterns. The following discussion pivots around these threads, followed by some general comments.

Feelings of the Participants

Regarding the first thread, participants spoke of their feelings both in the past and in the present. As children,

participants remembered experiencing anxiety, worry, disruption, resentment, jealousy, and empathy. These same feelings were found in studies conducted on children who presently have a chronically ill sibling (Bendor, 1990; Cairns et al., 1979; Gallo et al., 1991; Iles, 1979; and Martinson et al., 1990).

The dominant feelings, which most participants remembered experiencing as children, were those of feeling scared and alone. Feelings often were connected with a medical crisis or hospitalization of the ill sibling and revolved around a fear of the death of the sibling. This finding supports the results of two qualitative studies done on children who had a sibling with cancer. Martinson, et al., (1990) interviewed 16 well siblings of children with various types of cancer; these siblings were between the ages of 6 - 12. The emerging themes for the well siblings in this study included the presence of loneliness through separation from parents due to the child's illness, the feeling of being displaced and unimportant, the ambivalence of not knowing more about the disease, the threat of death of the ill child, and powerlessness experienced from not being involved. Bendor (1990) conducted a group session for five siblings of pediatric cancer patients; these siblings were between the ages of 9-12. The predominant themes in this group included feelings of loneliness, deprivation, displacement and vulnerability. It is interesting how

similar the dominant themes of the above two studies, conducted on children, are to those of the present study. The congruence between the findings adds validity to all three studies.

In the present, participants still expressed having many of the same emotions they felt as children; which include anxiety, worry, and empathy. The dominant feelings of this period, though, are anger, frustration, and guilt. These feelings were related to the participant's feelings of powerlessness and hopelessness. Many participants felt responsible for their ill sibling, yet at the same time expressed a lack of power in controlling the diabetic sibling's health behaviors or the progression of the illness. A few participants clearly expressed hopelessness concerning their sibling ever being healthy. As a result, some participants experienced feeling guilty about their own health or their freedom, in comparison to their ill sibling. This finding of the adult sibling's feelings of anger, frustration, and guilt supports the themes of the nursing studies done by Gerace et al., (1993) and Lively, Friedrich, and Buckwalter (1995) on adults who had a sibling with a mental illness.

To understand the theme of guilt found in the present study and in the above two studies, it is necessary to discuss briefly what has been written concerning guilt. Guilt is essential to form a conscience which allows people

to live together in a difficult and complex society. Guilt, though, can become excessive and unhealthy in many situations. Often people have unhealthy guilt reactions in situations in which they feel the guilt is not justified, and therefore they repress the resulting angry feelings. When the anger is repressed, frustration occurs, resulting in increased guilt feelings (Freeman & Strean, 1986).

Growing up we are taught to love our parents and siblings and not to be angry with them. Anger towards a loved one often leads to guilt because we believe it is wrong, and therefore, we must be bad. People feel that they have no right to be angry at a loved one who becomes ill because the illness was not deliberately chosen. Family members of chronically ill persons are often compelled to deny any anger or resentment and feel guilty if such emotions are revealed (Madow, 1988). Family obligations often cause members to lay impossible burdens on themselves. Family members feel a responsibility toward each other, often feeling guilty for another member's failures or problems (McDonald & McDonald, 1977). Is it any wonder that the theme of guilt occurs when studying adults who have a sibling with a chronic illness? Participants in the present study described many situations in which they felt responsible for their ill sibling.

To temporarily ease the guilt one feels, punishment is often sought from others or the self. Allowing oneself to

be manipulated is a form of self-punishment. One participant clearly speaks about being manipulated by her diabetic sister:

> When I won't go some place with her or if I can't take care of her little boy on a particular day or if I take a few minutes out of the week to go some where with a friend or something, she tries to makes me feel guilty like I should have called and asked her to go. Things like that. It is like she wants to control part of me. (Meg)

Consider the following passage in which the participant is punishing herself for what she perceives as selfishness on her part:

> So it has taken me a long time to grasp that I just don't have it. We all can eat healthy for a meal or two. But all these Thanksgivings and Christmases that we have had the chocolate cake and all the different things, they should not have been there. And it really would not have deprived anyone. There were substitutes. Especially with the new sugar substitutes. . . it was selfish. If we needed it, it would have been okay. It was kind of selfish that it was sitting there, but she (diabetic sibling) couldn't touch it. (Beth)

In the current study, one participant eased her guilt by increasing the caretaking of her ill sibling. Consider the following:

> I feel if anything would ever happen to them, I wouldn't have any reasons to feel guilty, because I did my best. . . It's just really, the main thing is, knowing if I take care of them if something happens, or if it does, I won't have anything to feel guilty about. (Meg)

Illness frequently generates anger in the sick person, who then becomes irritable and expresses it toward caretakers and loved ones. Significant others often become angry over the demands of the chronically ill person. Anger

can result from worry about the ill family member. A number of participants did perceive themselves as having to worry more about their diabetic sibling than the opposite being true. According to Madow (1988) "the anger is often not acceptable because the poor individual is, after all, sick and suffering, and the healthy spouse, son or daughter may deny it" (p. 77). People unable to accept their anger feel even more guilt. They attempt to deny the rage and turn it inward. If the cycle of anger-guilt-anger continues, physical illnesses, depression, or suicidal thoughts my occur.

Participant's Significant Relationships

The second thread in many of the issues discussed by participants concerned their relationships to other family members. According to Minuchin (1974) a family is a "system that operates through transactional patterns. Repeated transactions establish patterns of how, when, and to whom to relate, and these patterns underpin the system" (p.51). The diagnosis of a child with a chronic illness has a major impact on the family system, causing patterns to be disrupted. This disruption requires adaptation in the family. Most participants in the current study experienced the diagnosis of their sibling as a disruption, and then went on to relate how this disruption affected their relationship with family members and their roles in the family. Many of the participants spoke of how they and the

family worked toward protecting the ill member, whom they perceived as being vulnerable after diagnosis of the illness. This protection, or protective shield, was not removed even when the ill member entered adulthood. In fact, it was even often imparted over the protests of the diabetic person. Consider the following:

Tyler expresses his concern to his sister about not returning their mother's phone calls:

> Like I said she got mad about it. She said that you don't even let me breathe. I try to explain to her that we just got concerned for her because we love her. We don't want her in the hospital or anything like that.

Minuchin, Rosman and Baker (1979) believe that some families encourage somatization. They found that these families have four characteristics: enmeshment, over-protectiveness, rigidity, and lack of conflict resolution. They define enmeshment as follows:

> an extreme form of proximity and intensity in family interactions. . . changes within one family member or in the relationship between two members reverberate throughout the system. . . a dyadic conflict may set off a chain of shifting alliances within the whole family as other members get involved. Or one family member may relay messages from another to a third, blocking direct communication. (p. 31)

Members of enmeshed subsystems or families may be handicapped in that the heightened sense of belonging requires a major yielding of autonomy (Minuchin, 1974).

Minuchin, Rosman and Baker (1979) identifies three conflict avoidance patterns of involvement: triangulation, parent-child coalition, and detouring. They state that "in the first two patterns, the spouse dyad is split, whereas in the third pattern, the spouse dyad is united. With detouring, the parents submerge their conflicts in a posture of protecting or blaming their sick child, who is defined as the only family problem" (p. 33).

Results of this study reinforced many of the above theories and beliefs described by Minuchin. An example of enmeshment may be seen in the following passage:

> I guess Mom probably wanted me to look after him. . . he was suppose to have a snack when he would get in from school and she really didn't put me in charge of that job but I would try to make sure he did have one. . . If I thought he was upset, I was upset. I felt very protective of him and I guess I kind of wanted to go in his classroom with him and sit down with him and if they were going to have a party that day I wanted to be there and make sure he was okay with the party. Or I wanted to make sure if he was having one of his weak spells someone knew about it. I just felt like I wanted to be his shadow and be there to protect him. (Ellen)

Support for Minuchin's theories is greatest in the participants' statements regarding the present. Consider the following passages:

> I sort of have to protect J. . . It is not something that happens all the time. Just occasionally something will come up and I'll think I have to do that. It is a weird thing. (Karen) (overprotection)

I am worried about her taking care of herself and making sure she eats rights, does right, sleeps right, doesn't drink in excess amounts or whatever. I guess I'll always worry about her forever and ever and ever. (Jean) (overprotection)

Anytime something is wrong, someone is going to find out, and it is going to hit the highway. Make the trip around and everyone finds out. (Mark) (lack of direct communication)

We were side by side. Where she went I went. She couldn't get rid of me. . . we were just together. And we are still together. (Joyce) (enmeshment)

I was quite a mommy's girl, I realized that after I got married and moved away because it was devastating to me. But I realize it was really the best thing that could have happened to me. I think that has given me more insight into the relationship that my brother has had with my mother. It has never changed, because it has never been challenged, because he has never had to leave. And any problem he has ever had, every situation his life has ever had, he always runs to my mother. . .I just think he is much more dependent on mother. . . I feel if someday when we lose mother he will feel, I will feel the loss of a loved one, but not someone that I still need because of what she does for me. It will be just the loss of my mother. . . I still think that goes back to the fact that he was a diabetic and just set the tone, and she has just always done it for him. . . It is just like everything is still like it was when he was little, and his mommy is still always there to take care of every kind of problem. He wants to be independent, he almost resents the fact, I think, sometimes that she is as much a part of his life and he would like to break free of that. But it is almost like he doesn't know how, because she has been there for so long. . . She just worried about him so much and always wanted to be there for him. (Ellen) (lack of autonomy)

I feel like my brother is kind of selfish with his relationship with our mom. . . I can't really say that I am jealous of that relationship because that is not what I would want, but I guess I resent the fact when I tried to explain it to mom, she doesn't understand it. She doesn't see my side of it. I think she just thinks I am being jealous or silly or something. . .I have laid awake at night feeling, I have always thought that I wasn't jealous of them but now I have about decided that I am jealous of the time she spends with them. . .

> My husband used to say every time we came home from a visit I was depressed. I think that was a lot of it. I don't think I have the relationship with mom that my brother has. (Ellen) (lack of conflict resolution)

> My dad, I think, is very put out about the time mother has put into her children. I think he feels like he has taken a back seat through the years. . . There is a little resentment there in the amount of time that mother will think about J or talk about J or talks about his family or spends with his family. Because they are always there, and if they are not there, then she is over their house. And I think that really gets on my dad's nerves. . . I think sometimes he's not as tolerant because he has just had it up to his ears with J and his family. . . there is definitely some resentment there on my dad's part. He verbalizes that, but he won't verbalize that much to my mom, he just lets it fester. He shares it with my husband and me. (Ellen) (lack of conflict resolution)

Many participants described their families as having all four characteristics of families that encourage somatization. I wonder if a chronic illness in a family member crystallizes these characteristics in a family or creates them?

Participants became more acutely aware of changes in relationships with family members with the passage of time and the experience with the chronicity of the illness. Some also felt that the illness had prevented their sibling from reaching his or her potential. The passages below support these conclusions:

> In our relationship at this point we have come to a place where I think she - it used to be that they (parents) told me everything, every bad thing that they had to deal with J. I think she saw how that was affecting my relationship with J. . .He is not going to be my friend. We are never going to be compatible, I don't like him. She saw how that was my reaction to how he treated them. . . that was messing up our sibling relationship. Which we have never had a good

> one. . . she began to see how that was never going to be fixable if she continued to involve me in their problems with him. She does keep that separate now where she used to not. Now she does not tell me, 'oh I had to give J glucagon or whatever'. She does not involve me in that aspect anymore. Our relationship is more separate. (Amy)
>
> She (diabetic sibling) and my mother have a real close bond. They are very private. . .it is silly but at the same time it is probably a hurting that they would not trust me enough to tell me. . . it bothers me to think that they don't have enough confidence in me, enough trust in me to open up and share things with me. It is like they have to have a private life. . . she really developed a bond with my brother. . . I think that she values his relationship more than she even values mine. That has always bothered me too because he didn't do as much, I felt like, or wasn't there as much for her as much as I was. And I still wasn't appreciated, still am not. (Sarah)
>
> She has a hard personality as a result of this. She used to be real jovial. It has been real hard to watch her deteriorate from that. . . I can see the change in her, her personality and things like that. What she has become as a result. . . she is not nearly like she used to be. . . I know she don't enjoy life, not like she did. . . But I feel real sad for her because she is only 49 years old and I don't think that is old. . . So I think knowing that she has so much life potentially ahead of her if things were to go fairly descent for her. . . she has conceded. . . that there is not going to be much else. (Sarah)

The theme of changes in relationships, as a result of a chronic illness, once again supports the findings of the two nursing studies done by Gerace et al., (1993) and Lively, Friedrich, and Buckwalter (1995). It is extremely interesting how these two studies, involving mental illness, yielded similar themes to the present study of adults who have siblings with a physical illness. Similar themes in these three studies included changes in relationship with family members; grieving over the lost

potential of the ill sibling; feeling that the ill sibling is the central focus of the family, thereby depriving other members of time and attention; and the illness impinges on spouses and children. The long-term impact a child's illness has on the well siblings is consistent across all three studies.

Coping Patterns

Coping strategies are behaviors that are used for managing stress (Holaday, 1984). According to Holaday (1984) "coping strategies serve three functions: change the situation out of which problematic experiences arise, control the meaning of the problematic experience after it occurs, but before the emergence of stress, or control the stress after it has emerged" (p.364). Many of the coping strategies utilized by the participants in the past and the present would be labeled as emotion-focusing coping by Lazarus and Folkman (1984). This type of coping is directed at regulating the emotional response to some problem and occurs when there has been an "appraisal that nothing can be done to modify harmful, threatening, or challenging environmental conditions" (Lazarus and Folkman, p. 150).

Participants described using the following emotion-focused coping strategies as children:

One participant uses avoidance to cope with his sister's hypoglycemic reactions shortly after she was diagnosed:

> If something happened I would leave or I would just shun the problem, sweep it under the bed. . . She would

> always want to go places and you would have to come up with excuses not to take her. (Tom)

Meg coped as a child by keeping an object owned by her sister or parents close to her:

> If it was an item of theirs, I wouldn't want anybody to bother it. I would want it left the way it was. . . it was just like if they had their hand print on it, or just knowing that they had held it, or that they had kept it close to them, that I would keep it near by me. . . Like if they were to give me something that only they had touched, I wouldn't want anyone else to have it, or touch it, or pick it up. If someone touched it, it would mean someone, maybe, lifted their spirit off of it.

Two participants coped with the illness, as children, by keeping quiet and not sharing any information about it to anyone. Both explained that this was not the way they had preferred to deal with it, but related that it was the way their ill sibling had instructed them to handle it. This finding does not support the conclusions of Gallo et al., (1991) who found that younger siblings tended to be more secretive about the ill child's illness than the older siblings. They explained that as "siblings get older they demonstrate a more sophisticated understanding of the causes of illness, which may mitigate the need to hide the chronic illness from others" (p. 23). This study suggests that it may not have to do with the age of the sibling but rather with the well sibling's desire to abide by the wishes of the ill child.

Examples of other emotion-focused coping strategies used by the participants in the present may be seen in the following passages:

> The majority of times I can't ponder on anything that is debilitating to me. I have to let go. I have to accept it for what it is, and that is the way it is, and I have to let it go. That is the way I survive. I can't allow feelings to engulf me or take advantage of me or debilitate me. I have to go on. . . I don't allow myself to think of her problems. I don't want to think about something I can't change. I have to put it back somewhere. (Sarah)

> She is different from point á to point z. When I say she is the black sheep of the family, that is no exaggeration. We, all three sisters R, P, and myself were all born in April, M is in January. Everything, everything literally about her is totally different. To list them I don't know if I really could. She is the only one of us that has a disease. . . Mother and dad both are born in July, M is born in January. Everything is just totally different about M. We all get up, put make-up on, bathe and wash, do the normal routines. M, it does not phase her one bit to get out of bed and go. She is out of there. (Carol)

> Because when I moved away from home I washed my hands of it. I told them I am not going to get sucked into this. I am not going to deal with him. (Amy)

When Meg's mom and dad are arguing with her sister about eating enough to prevent hypoglycemia she copes by withdrawing:

> I felt just like leaving and I did, because I had to get out of it and I did.

Others coped by minimizing the illness:

> It is not the worst thing in the world that could happen. . . I have a brother who just happens to be a diabetic, it is no big deal type of attitude. There are things that could be a lot worse than being a diabetic and I am just thankful that this is something that he can take care of and keep going. At least he doesn't have cancer and have to go through chemotherapy and anything like that. . . When I see someone that has

> something a lot worse than having diabetes, then diabetes seems like nothing to me. Even though I know it is. (Fran)

> You know this is workable. You could have something like MS or CP or something really horrible where you couldn't do for yourself. But you can. I know from my education it is a grieving process from what you have lost. But I think he was left with so much, you know compared to some. It is not like cancer or something like that. (Amy)

> Cancer is something that can kill you. It is not something you can control or anything. Cancer, when you have it, you depend on a doctor for chemotherapy possibly, or radiation and other types of treatments to save your life. While diabetes is something that you can control with your diet and your shots and your glucose on a regular basic. (Tyler)

One participant uses positive comparisons:

> She is just like you and me, but she still, she is the one taking shots. . . I guess I try to make her feel normal, I guess I want to. I hope I do. (Jean)

Many participants expressed being powerless in controlling their siblings' behaviors and the progression of their illness. According to Lazarus and Folkman (1984) "if a person is helpless to deal with a demand, stress will be relatively great because the harm/loss cannot be overcome or prevented. If the person has a high stake in the outcome, meaning that it touches a strong commitment, helplessness is potentially devastating" (p. 35).

Another construct of Lazarus and Folkman (1984) that may add to the stress of participants in this study is that one cannot control a situation that is not predictable. The medical course of IDDM is often difficult for the physician and patient to control. The adult well siblings certainly

have little control over the medical course of the illness and the compliance of the ill sibling. Thus, it can be easily understood why adults who have a sibling with IDDM experience an increased amount of stress. Adding to the well sibling's stress is the unpredictability of the medical crisis of the diabetic sibling. According to Lazarus and Folkman (1984) "not knowing whether an event is going to occur can lead to a long, drawn-out process of appraisal and reappraisal, generating conflicting thoughts, feelings, and behaviors which in turn create feelings of helplessness and eventual confusion" (p. 92). All participants in the current study described stress concerning their sibling's unpredictable medical future. Participants describing the most stress, though, were those who perceived their sibling as not experiencing personal and/or medical control over the diabetes.

An important factor leading to the stress of adult siblings of a chronically ill person is role conflict. Conflict arises when in order to satisfy the demands of one role, the requirements of another role must suffer (Lazarus & Folkman, 1984). Some participants experienced this role conflict as shown by the following passages:

> Sometimes they (parents) want me go and check and make sure that she got food, that she eats. I have my own family to take care of. I can't take care of her anymore. . . I have my own family to take care of now. (Meg)

> We don't share family gatherings anymore. We used to have them all the time, but we don't have them anymore. . . My daughter comes first. (Sarah)

> My life is devoted to my husband. Anything that makes him happy I do. I go out of my way. She (diabetic sibling) doesn't understand that now. She and I, when I lived in Atlanta I would come in every other week-end, and once I met D (husband) my life changed totally. When I came home for the week-end I spent three days of that with him and she doesn't like that. She'll tell me 'you don't do anything with us anymore, you do everything with D'. . . She does not like the fact that if it comes to doing something with my sister and something with my husband, nine times out of ten, I'll pick something with my husband. (Carol)

According to Lazarus and Folkman (1984) "the persistence of a chronic stressor can give the person the opportunity to learn to deal with its demands, or to deal with it by avoidance or distancing" (p. 100). Although the majority of participants in this study chose to deal with the stressors associated with their sibling's illness by trying to meet the demands of the illness, a few chose to avoid and distance themselves from their ill sibling. Distancing oneself from their ill sibling supports the findings of Gerace et al., (1993) who found that siblings felt guilty about wanting to get away, yet felt compelled to do so for their own well-being.

General Comments

Bush (cited in Drotar and Crawford, 1985) hypothesizes the following:

> Well siblings' perceptions of similarity or identification with their ill sibling relate to their psychological adjustment. Adjustment is expected to be

> poorer among siblings who perceive themselves as either extremely similar or extremely dissimilar to their ill sibling than among siblings who demonstrate more balanced perceptions of both similarities and differences. The rationale for this hypothesis is that siblings who perceive themselves as very similar to their ill brother or sister are more likely to be over identified with them. On the other hand siblings who perceive themselves as very much unlike their ill sibling may be defending against underlying fears of identification which may reflect a maladaptive level of anxiety. (p. 657).

The present study supports the above hypothesis. In general those participants that appeared to have the most difficulty with adjustment to their sibling's illness were those who described themselves as being very similar to or very different from their sibling. One participant who described herself as being very much alike and very close to her diabetic sibling, became so distraught during the interview that she could not finish. Another participant who described herself as being very different from her diabetic sibling was consumed with anger towards her brother and his inability to take control of his illness.

Relevance to Nursing

Most of the participants of this study were confused, at first, about why a nurse researcher would be interested

in them. Most wondered why the research was not being done on the ill sibling. This initial reaction came as no surprise to the researcher, knowing that seldom were the participants the "designated patient". The findings of this study give nurses a greater understanding of the long-term impact chronic illness has on the entire family, in particular, on the well sibling. The adult well siblings' viewpoint has long been a missing link in our understanding of the stressors of a chronic illness on the family. These findings emphasize to us the importance of holistic nursing. As defined by Levine (cited in Artigue et al., 1994), holism "means that human beings are more than and different from the sum of their parts. Perceiving the wholes depends upon recognizing the organization and interdependence of observable phenomena" (p. 201). Holistic nursing, and the importance of caring for the entire family, has been espoused by nurses for many years. The present results, though, remind us that we still have a long way to go from understanding the importance of holistic nursing to implementing its process. Nurses in a variety of settings have the opportunity and the responsibility to assist well siblings throughout the course of the ill sibling's chronic illness. The following discussion proposes various areas to assess, and presents appropriate nursing interventions.

Many participants expressed a lack of professional input pertaining to their knowledge of diabetes. Some

learned by watching and receiving instructions from their ill sibling, others learned through reading. The following statements concerning how the participants learned about the illness confirm this:

> Just from J talking about it and watching her take her shots, draw up her insulin and having insulin in the refrigerator all the time. (Karen)

> I saw her do it so many times and she told me exactly how, and I just did it. . . I never picked up books and read about diabetes. I guess it is just being around it, living with it. Maybe hearing my mom talk about it. Which I know my mom probably has read a lot about it. I guess seeing the every day life of a diabetic that you learn. (Jean)

> I was very interested in diabetes and learning more about it, so I did my report on that, and I learned a lot through books. . . I wanted to learn as much as I could about it in case he ever did go into an insulin reaction, and I would know what to do. (Fran)

Only one participant remembers having any direct input from a professional concerning his education about the illness:

> Doctor pretty well explained it to all of us and what we needed to watch for or look for. He met with us it seems like and told us about it. (Mark)

A significant finding of this study is the necessity of direct communication and education by health care providers to all family members, including well siblings. One participant clearly articulated this importance:

> At first I thought it was funny. She played pranks and I thought, well she is into one of her moods. But then when she started screaming and acting really wild, I got really scared. And later I thought, what if I hadn't thought, no one had prepared me that this might happen. I just happened to put two and two together and know that I should do that. So what if I hadn't thought that this was what it was. And I realized how close to really death she could become. So, I guess, looking back if I would say anything should have been

> done, it should have been that I was included in, in all the different dangers that were there. Which I don't ever remember anyone telling me. (Beth)

This study's finding of the importance of communicating directly to all family supports the results of Main, Gerace, and Camilleri (1993). They found that lack of communication and education by health care providers were two of the major obstacles that prevented families from obtaining the information necessary to assist them in caring for their schizophrenic family member. They felt that families were often at different stages in their readiness to accept information. Thus, they concluded that health care providers needed to understand that although a family member may not seem interested in receiving information at a particular point in the patient's illness, they may be quite interested in learning more in the future.

This conclusion is extremely important for well siblings who, at different developmental levels, may experience various interest levels of knowing about the illness. Nurses cannot assume that adults, who have grown up with a diabetic sibling, possess correct information concerning the illness. Well siblings may not seek information concerning the illness until they reach adulthood. Therefore, it is imperative that nurses continuously assess the knowledge level of well siblings and supply them with accurate information as appropriate.

Nurses also are responsible for teaching parents how to communicate to their well children about the ill child's illness. One participant remembers everything being explained to her through her ill sibling's perspective:

> I remember mom and dad sitting us down and trying to explain to my older brother and myself about what this could mean, and about how we had to be careful. Try not to eat candy in front of him and try not to tempt him with sweets and things that he shouldn't have. . . She would say it is not good for J to have this so you shouldn't have it. . . It was always to help me to understand J, how it would make J feel if he saw me eating this or having that. 'I can remember hiding in the kitchen eating things. . . She naturally felt more sorry for him because of having the diabetes and having to have the shots. . . I do think that it is important for the whole length of the relationship to try to, try to understand how everybody feels and what the impact is on everybody. I remember when my mother used to talk to us about it, but it usually was from J's viewpoint. It was like don't eat that in front of J. Don't do that here, that will make J mad, that kind of thing. And at the time I don't remember it bothering me very much at all, but I think it would have been real important to see how it is making all the other children feel too. The fact that he is not the only child in the family, that are having to give up certain things and be careful of certain things because of the illness that the one has. (Ellen)

The above passage reminds us that there is a distinction between information giving and communication. Family members and health care providers often convey to the well siblings information concerning the illness and the impact that illness has on the ill person. Many psycho-educational programs that include siblings aim at helping the well siblings understand the illness and what the ill person is enduring. This type of communication, although important, is information sharing and not true

communication. True communication involves mutual understanding and empathy. Everyone wants to be understood. The above participant reminds us that nurses, as well as parents, must be cognizant of the feelings and perceptions of well siblings. We must attempt to understand the impact the illness is having, not only on the ill child, but also on the well siblings. By recognizing the well siblings' struggles and hardships parents/nurses may give them the modeling they need to gain empathy and concern for others, greater personal maturation, and increased family cohesion.

Results of this study may help nurses recognize when well siblings are struggling with feelings of guilt and anger. Therefore, a necessary nursing intervention for adults, who have a chronically ill sibling, is to help them express their anger in order to help relieve the guilt that they may be experiencing. We must help family members recognize anger as a major source of guilt. We must also help family members recognize that everyone, at times, has angry thoughts towards significant others, and they are not bad or monsters for having these feelings. According to Madow (1988) "until people recognize their anger and realize that it is normal, regardless of it not being logical or reasonable (emotions are not always logical), that they will be relieved of their guilt and can deal with their situations as required" (p.71).

It has been found that it is difficult to convince some family members to give up control of caregiving, because they feel that only they can provide proper care (Smith, Smith & Toseland, 1991). This is an area that nurses must evaluate in regard to adult well siblings. Often because of the concern or caregiving that the well sibling was providing the diabetic sibling, the emotional health of the participant was affected. This was evident by the tears and sad affect of many of the participants. Helping family members to relinquish responsibility and thereby give control to others is a challenge to all health care providers. Failure to meet this challenge will only result in more casualties.

Results of this study reinforce the fact that the stressors of chronic illness affect all family members, including the well siblings. The methodology used in this study allowed participants to clearly articulate the stressors and burdens they perceive as generated by their adult sibling's chronic illness. I believe that learning about the stressors and burdens of adults who have a sibling with IDDM would surprise most nurses, for seldom are adult well siblings perceived by nurses as being vulnerable to the stressors of their adult sibling's chronic illness. Stress can increase one's susceptibility to physical and/or mental illness. How one evaluates and copes with the stressors of a chronic illness will influence one's quality of life. It

is imperative that nurses give care to the family, not just the designated patient. One way nurses can reduce the amount of stress on family members is simply by recognizing their stress and attentively listening to their concerns. Attentively listening will enhance a trusting relationship which is necessary for family members to sense empathy and concern from the nurse. Only with this kind of rapport will adult siblings reveal their true concerns to the nurse. With this knowledge, nurses may then: help adult siblings reduce their stress, provide information, offer support, and help alleviate guilt and/or unreasonable feelings of responsibility or powerlessness. Nurses must be prepared to provide counseling, education, and anticipatory guidance to adults who have a sibling with a chronic illness.

Suggestions for Future Research

The current study represents a descriptive study of the experience of having a chronically ill sibling; specifically, one with IDDM. Prior to this study, the phenomenon of the long-term impact a child's chronic illness had on the well siblings was poorly understood. This study is one of only a few that have been done in nursing on adults who have a chronically ill sibling. It was hoped that a phenomenological investigation would provide a foundation to understanding the long-term impact of the experience of having a chronically ill sibling. The present methodology was chosen because of its commitment to a

rigorous description of the phenomenon. The hope was that from this research more specific research projects could be developed to further the understanding of having a chronically ill sibling.

One finding of the current study was that the experience of having a chronically ill sibling can be related to situational factors and unique participant characteristics. The relationship of the thematic structures of having a chronically ill sibling to different life experiences could be investigated. For example, individuals who have a chronically ill sibling, and whose parents are deceased, may be interviewed regarding their experience of role reversal or of increased care giving responsibilities. Adult siblings of persons having chronic illnesses other than IDDM, could also be investigated regarding their experience of having a chronically ill sibling. Adult siblings of different races and cultures could also be selected as participants.

The present study revealed a theme of guilt in relationship to having a chronically ill sibling. Although much has been written on the general topic of guilt, a specific discussion of guilt related to being healthier than one's sibling is missing. Further investigation is necessary into how the well sibling's guilt for being healthy affects their mental health.

Another important theme concerned participants' perceived differential treatment of their ill adult siblings by parents. Researchers agree that perceived differential treatment of siblings by parents affects the quality of the sibling relationship and parental interactions (Dunn & McGuire, 1992; Furman & Buhrmester, 1985; Powell & Gallagher, 1993). Future research must continue to explore the domain of preferential treatment of adult siblings by parents. Research needs to focus on such perceived preferential treatment in relation to the interaction between siblings, willingness and quality of caregiving by the well sibling, and the effect on the mental health of both the ill and well sibling.

Finally, the current study revealed a theme of the well sibling's concerns about his or her sibling's future, health and possible early death. These concerns generally lowered the well sibling's sense of control, and generated more concern for one's sibling than is likely in the general population. Future research should focus on answering the following questions: How often and in what ways does the uncertainty of a sibling's future influence an adult's life and relationships? Are adults who have a chronically ill sibling more acutely aware of their own mortality?

Future research must continue to examine the relationships between adult siblings in which one has a chronic illness. Factors to examine include the type of

relationship vs health regimen compliance of the ill sibling or type of relationship vs amount of guilt experienced by the well sibling.

Well siblings, in most cases, will outlive their parents and probably will to some degree be or feel responsible for the care of their ill sibling. Future research should explore the impact that this caring may have on the well sibling's mental health and family. It is hoped that this study will encourage nurses who research care givers and chronic illness to include well siblings both as the sources of data and as targets of intervention.

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APPENDICES

APPENDIX A

INFORMATION AND CONSENT FORM

You are invited to participate in a research project. The purpose of this study is to explore the experience of having grown up with a chronically ill sibling. For health care providers to better care for families who have a chronically ill child it is important to know what impact the illness had on the well sibling. The best source for this information is from persons who grew up with a chronically ill sibling. This study seeks to ask adults who grew up with a sibling having insulin dependent diabetes mellitus (IDDM); are no longer living with that sibling, and have not lived with their family of origin for one year prior to the study, about the experience. The interview will be conducted by the investigator who has worked with people in health care for many years.

You will be asked to participate in an audiotaped interview that will last approximately one hour (maximum of two hours) in a place of your choice. You will be asked to share your experience of what it was like to grow up with a chronically ill sibling. Subsequent questions will follow and will be based on your comments and responses. This interview will be audiotaped so that the investigator can use your exact words to compare with words of others who have grown up with a chronically ill sibling. These interviews will be transcribed into written form to allow for analysis. Your name will not appear on the tape or the transcript and will be known only to the investigator and kept in a locked file with tapes and transcripts at the University of Tennessee, College of Nursing. You may be contacted by the investigator following the interview and during the analysis to clarify the interpretation of your experience. Upon completion of this study, the transcripts and code book, linking your name to your tape will be destroyed along with the tapes themselves. No incentive is available to reimburse for your time and effort in participating.

The nature and direction of the interview will be determined by you and the investigator and will unfold as the interview progresses. Some areas of exploration have the potential to produce some concerns, anxiety, or embarrassment. You are free not to answer any questions regarding these feelings. You are free to choose not to participate in this study or you can withdraw from this study at any time without penalty. Your audiotape will be destroyed upon your request to the investigator or co-investigator whose phone numbers appear below.

Any and all information you provide will be kept in confidence. Your name will not be used in any reports, nor will your words be linked or traceable to your name.

_____	_____
Signature	Marilyn E. Smith, RN, MSN,MSRC Investigator

SUBJECT'S STATEMENT

This study has been explained to me and I voluntarily consent to participate in this study. I have had an opportunity to ask questions and understand that I may ask further questions at any time in the future by contacting the investigator named above. I can withdraw from the study at any time without penalty. I have received a copy of this consent form.

INVESTIGATOR: Marilyn E. Smith, RN, MSN
Doctoral Student,
University of Tennessee, Knoxville
College of Nursing College
(615) 974- 7581

CO-INVESTIGATOR: Sandra Thomas, RN, Ph.D.
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APPENDIX B

CONFIDENTIALITY STATEMENT

I, _____ agree not to discuss or disclose any of the content of the transcripts analyzed by this research group for the dissertation entitled "Protective Shield: A Thematic Analysis of the Experience of Having an Adult Sibling with Insulin Dependent Diabetes Mellitus".

APPENDIX C

DEMOGRAPHIC DATA FORM

Initials _____

Gender _____

Age _____

Marital Status _____

Years of Education _____

Occupation _____

Age of ill child at time of diagnosis _____

Your age at the time of ill child's diagnosis _____

Length of time living with ill sibling _____

APPENDIX D

SAMPLE TRANSCRIPT: ELLEN

I: Can you tell me what it was like for you to have a chronically ill sibling?

R: I think the main thing I would remember is concern for him and there was a lot of anxiety at the beginning out of fear that something was going to happen, because at the beginning he had a lot of episodes of insulin shocks and that was a very scary experience for me. My mom worked and sometimes he would feel it coming on and sometimes he wouldn't. And most of the times he didn't feel it coming on, it would catch us off guard. We would be watching T.V., and he would make some really off the wall, some strange comment. And I would look at him and I could tell. And if you could catch him in time, you were okay and you would give him some juice or something. But if you couldn't, then it would get really bad. And he had some really bad episodes when I was with him by myself. And I felt like I was responsible. And I would somehow blame myself sometimes if it got out of hand before I could catch it. And he would always run from us like we were trying to hurt him, his vision would be impaired and he couldn't see and he would fall. He would throw things at you. I know one time he threw the phone at me and it hit me in the ankle. And he would feel real bad after he came out of it and he would apologize. He would always be real shamed that he had gone through this episode. He would break a lot of things in the house at times. But that was in the beginning when we were still trying to get the insulin regulated and all that kind of stuff. But concern for him. I remember it was at Christmas time when he was diagnosed and he was 9 years old. And when he came home from the hospital he couldn't have any of the treats or he didn't even like fruit cake but I remember distinctly that we had fruit cake at the house and he said "mom, will I not be able to have any fruit cake." And she said, "no". And he said, "well I don't really like it but I was kind of wanting a piece of it". And I remember a lot of different things like that. I remember he was younger than me and I was protective of him at school and I know that we would always worry if they were having a party at school or something and they would forget to bring something he could eat or they would forget to tell my mom that the party was going to take place. And we would worry that he didn't have anything to eat when the other children were having something to eat, a snack in the classroom. And we were always checking in his bag to make sure that he had his little sugar cubes that mother packed in aluminum foil or a mint or something in case he felt, we called them weak spells coming on. And I was worried about him. That was

the main thing I remember feeling a kind of, I guess, a motherly instinct towards him because I was older.

I: You said you were concerned about your brother, can you talk a little more about what that concern was like for you?

R: Yes, I was concern of course about those weak spells he would have because I was afraid he would hurt himself when he was going through them. And there were quite a few of those episodes. As I recall my mother worked, sometimes I would call her at work while it was going on, sometimes I would call my neighbor next door and they would come over because we really physically had to restrain him, hold him down to get some juice into his body. One time when he was older I remember he was at his girlfriend's house and he almost, he actually went into a diabetic coma and we had to take him to the hospital and give him an IV. I was concerned and I didn't even realize in the beginning years that it could really be controlled. I kept thinking he would die. He would have one of these episodes and he would not come out of it. I just remember feeling so sorry for him in the beginning, thinking that he would never have a normal life. But as it turned out he has had a normal life. And he has two children. He is on two injections a day. He is a severe diabetic, he is not a brittle diabetic in that his can be controlled with the medication and he has lived a normal life. But I worry a lot about him now because he is getting older and the long term effects that this disease has had on his body which can cause blindness, heart disease and all these other things. I keep wondering, you know, if he might possibly have problems like maybe kidney failure or something like that, amputation that leads to an injury that doesn't heal. I remember he never, my dad would never let him mow the lawn or trim or anything like that because they were so afraid. He was always kind of babied because my parents were very protective of him of course. My older brother and I never really seem to feel any resentment. I remember trying to think about that after I talked to you and knowing we would do this interview. But I don't really remember resenting the fact that there were some things he was not asked to do because we were <u>all</u> protective of him. And at school I remember we went to school together and I always looked after him. I tried to make sure you had everything he needed. So that is basically what I remember as far as the concern part. But I never had any feelings about that, it never bothered me that maybe he was babied a little more than I was because I always understood that, probably because I was older. If I had been closer to his age I may have resented that a little bit. Lots of time at meal time he had to have different things because his food had to be prepared in special ways. I do remember sometimes that I thought that his food looked better than mine. I

would think "Gosh I wish I could have that." I would think his looked a little better than mine looked. He would get something grilled in the oven and we would be having beans or something else like that. But I would think his looked a little bit better.

I: You stated that you protected your brother at school. Can you talk about a time when you felt you had to protect him?

R: I remember, this may not have been particularly to do with diabetes. But he did have one teacher one year that for some reason that he was kind of afraid of her. Her name was Mrs W. which is funny because my name is Mrs W. and I am a teacher. I would want to walk him to his classroom in the mornings, but for some reason she decided I didn't need to do that anymore. She would meet us half way up the hall, she would make me stop, and let him continue there. I would wait in the hall and he would turn around and wave to me when he got to the door. He would always have tears in his eyes and I knew it would make him feel better about his day if I could just walk him into his classroom. That is one thing that stands out in my mind. I would worry about him getting hurt at school or I would worry about him having one of those weak spells as we called them because.. . You know I was afraid if the teacher did not notice it or did not realize what was happening it could get real severe and he would have to go to the hospital. So that type of thing is what I worried about. And as he got older we worried that sometimes when he took tests and things like that he was not performing at his best level because maybe sometimes his condition was interfering with his performance in the classroom. And we worried about that too.

I: What were you feeling when you saw him with tears in his eyes at the classroom door?

R: I would have tears in my eyes. I guess I felt what he felt. Like I said I had a lot of motherly instinct that came out. I guess mom probably wanted me to look after him. We walked to school together because we lived close to the school and I guess if he had anything on his mind that was bothering him he would discuss with me on the way to school. So when we got to school I couldn't even walk him to his room because that teacher would not let me. We had to part company in the hall. If I thought he was upset, I was upset. I felt very protective of him and I guess I kind of wanted to go in his classroom with him and sit down with him and if they were going to have a party that day I wanted to be there and make sure he was okay with the party. Or I wanted to make sure if he was having one of his weak spells

someone knew about it. I just felt like I wanted to be his shadow and be there to protect him .

I: And when the teacher would not let you go to the classroom with him, can you talk about what that was like for you?

R: I was very angry with her and I didn't understand it. And she feels I was babying him and he was at an age where he should be able to walk down to the classroom by himself and he didn't need me. And she would come back out after he went in the room to see if I had left so I would turn around and leave. I guess she was watching to make sure that I would not come down there. But to this day I don't understand why it bothered her to let me walk him to the room and watch him go inside, and then tell him goodbye at the door. And if I could see her today I would tell her that. I am an educator myself. If that gave him that little extra bit of confidence and comforted me I don't know what the problem was. She was, I just felt she was not a very understanding teacher. She was the type that would smack them on the hand with a ruler. That was another thing I would worry about. I would worry that he would have one of his weak spells and maybe he would not be listening properly and she would give him a smack on the hand with the ruler or something. I just worried about him in her room that year because I don't think she was a very nice (Laughs). So that's how I feel about her.

I: You mentioned that you felt responsible for your brother, can you talk more about that?

R: Well there again I guess because I was older. I think mom would say, it's kind of hard to remember back to all that time, but he was suppose to have a snack when he would get in from school and she really didn't put me in charge of that job but I would try to make sure he did have one. And then, of course she was giving him his injections at the time, he hadn't started to give them himself, and I certainly never did give him his injections. Then in the summer when we were there, she worked in a store and sometimes she would be able to come home for lunch and sometimes she wouldn't but she would always leave what he was suppose to have for lunch and then he and I, you know, would prepare it together, warm it up because we were very careful that he ate on schedule. I feel I played a very important role there. I helped make sure that he ate on time and that had to coincide with the time he received his injections. And then sometimes he would have a snack, drink some juice, or eat a piece of fruit, or something like that. Again if he had been outside and played longer than normal or something like that, there were a lot of extenuating

circumstances that could make that insulin over react or whatever. He would need more sugar in his system. It just seems that, after one of those episodes took place we would all be able to sit down and analyze and figure out why it had happened. But I would always think why didn't I pay more attention, why didn't I notice this was happening before. Because he would lay down on the couch and he had been watching T.V. and he usually would get real quiet right before whatever happened. It would seem like one minute we were talking and the next minute I would look over there and I could tell that he was getting kind of drowsy. He was okay if you left him alone but if you tried to get him to sit up and drink some juice he would get real argumentive with you and he eventually would get up off the couch and take off running. One time he fell down the basement stairs, or one of us did. We may have fallen down the stairs together because I was trying to get out of there. I would feel so sorry for him because he would think we were trying to hurt him and he would do anything to get away from us. He was just like a scared animal. I don't know if that is how all diabetics react to it, but you would just have to physically get a hold of him and get something into his body. I was always in a panic to do that because I think if I don't get it into his system then he is going to go into a coma and we are going to have to get him to the hospital. I felt responsible. Mainly I felt responsible if I was home with him by myself, or even if my older brother and I were there together sometimes we would do that together. I am making it sound like they were frequent, but they weren't. They just stand out in my mind because they were so scary. It was a very scary time. And when I think of his childhood that is what I think of sometimes. But before he was diagnosed he was real grumpy and we were arguing a lot more than usual and he was having to get up at night to go to the bathroom a lot. Like I said I remember his appointment was around Christmas time and we were over at my grandmother's and he was playing with a little pool set that he had gotten for Christmas. The three of us were playing with it and if he would lose he would get real mad and throw his cue stick down and everything. And I remember mother putting her arm around him and saying we have an appointment this week and we are going to try to find out what is troubling you, what is bothering you. So when they put him in the hospital for tests and everything, in the beginning they thought he had leukemia and of course my mom and dad, I'm sure, were very upset. She didn't tell me this until later, but we were really kind of relieved when we found out that it was diabetes because it was something that could be handled. I remember mom and dad sitting us down and tried to explain to my older brother and myself about what this could mean and about how we had to be careful. Try not to eat candy in front of him and try not to tempt

him with sweets and things that he shouldn't have. In the beginning we just didn't buy anything like that. S and I didn't eat it either because J couldn't have it so we just didn't get it. And we understood that. And of course I am sure we would buy it and eat it, not in his presence and that kind of thing. Mother never made desserts anymore, we never got pies, we never got cakes, we never baked cookies. I am sure I kind of missed that. (Laughs). But that was a small price for me to have to pay for what J was having to go through. But that is probably the only thing I might of felt like I gave up, you know, I remember I tried to learn to like, he used to drink Tab. That is what he would drink. I would try to like to drink it but I could never drink it, I didn't like it. And we would drink juice and they came out with nutrasweet things. You know that was wonderful. But back in those days there wasn't that much you could buy that was artificially sweetened, so we figured we gave up everything as far as sweets in our house. But I remember asking mom if he was going to die and she said no. That this was something that could be controlled. They kept him in the hospital for a few days trying to get his insulin regulated and then they brought home all these stacks of menus and things from the school cafeteria, I mean the cafeteria from the hospital. He had to have specialized seasoning and everything. We would try to act like everything he was eating was so good and that we wished that we could have that and that kind of thing to make him feel better about eating it. And before he came home from the hospital we went through the house and got rid of our Christmas stockings and got rid of all the candy and everything. Of course he hadn't eaten all of his and he asked us if we had thrown it away and we told him that we did. There were a lot of sad things about that when he came home. He had to have two shots a day. He has had two shots a day since he was nine and he is 38 now. So it has been a long time.

I: You mentioned about J going into a coma. Can you talk about what that was like for you?

R: I cried. It was very scary. I believe the first one I remember was on a Sunday. We had been to church and we had come home. I can remember this, that mother was running around to get the meal on the table because he needed to eat. And we would usually go ahead and give him some juice or something when we got home from church. Of course he was young and he wouldn't remember to go in and get it but mom and dad stayed right along and tried to get him some juice. And we had come home from church and it seems to me he had gone upstairs to his room and he just laid down on his bed. And when mother called us all to lunch and he wouldn't come. So mom and dad went flying up the stairs to check on him.

Or maybe I went up to do it and he was on the bed. He had gotten pretty far along in one of his comas and we hadn't really watched that day. S and I went up to his room and we were standing there watching mom and dad work with him. There was orange juice everywhere. He had knocked it out of their hands. It was very, very scary because I remember seeing that and I was always afraid that he was going to die. Because I was afraid that he wouldn't get any better and he wouldn't come out of it. And they would talk real sweet to him and coax him and try to get him to drink and tell him that they loved him and that they were trying to help him and they would say "if you would just drink a little bit of this you will feel so much better." I just remember thinking that was so sad and seeing how sad my parents felt. And how I am sure they worried about him. It made me feel sad and it made me feel concerned because we were a very, very close family. Very close.

I: You were aware of how concerned your mom and dad were?

R: Yes. And that had a major impact on me and it made me afraid. And even though they would try not to talk about it much, certainly not in front of J, they would try to reassure me. I was always afraid about it, fear about it, until a lot of time passed and finally knew that we were going to be able to deal with it. But in the beginning I thought it was a very frightening thing. I felt like it was going to change our whole life. I didn't feel like our family was ever going to feel normal again, because we always had to be on this schedule and if you got off the schedule then it would mean that J would have one of these attacks. When we even went on trips we had to pack the insulin and if we were going to go on a day trip, that was another thing we worried about was like his field trips. He wouldn't get to go if they were going some place where my mom couldn't meet him. He might not be able to get his shot or something like that. It was just a lot of things that had to be dealt with and we all pitched in there together as a family and tried to help with that. I certainly wasn't given more than my share of responsibility, probably any at all, other than the fact when my mom worked we were all there together and I just felt that I needed to pay attention to him and how he was feeling because when he was young it was like he could never feel it coming on. Or if he did, he would say I just thought I was tired and wanted to go and take a nap. And that was the way his would begin. Now he can kind of feel it coming on, of course. He knows if he needs to get something to eat, get something to drink, he never has a problem now like that. But on up through high school, off and on, he occasionally would have a problem that would just kind of slip up on him. When he was little in the beginning that is when I most remember those

episodes, the really scary ones. I would really be frighten.

I: You stated you saw the concern your mom and dad had and that had a real impact on you. Can you talk more about that impact?
R: Well I felt sorry for my mom and dad and I guess I would just think that I wish there was a cure for it. And in my home life I just held on to the hope that they would find a cure for diabetes. We have always realized that we were lucky that it was not leukemia, it wasn't any form of cancer. It was something we could live with. But I always felt sorry for mom and dad because I knew they were sad that he was having to live with this. And I knew that it made them overprotect him of things sometimes and sometimes I felt that he was a little bit more of a mommies boy than he would have been because she was so protective of him. Even to this day I have felt she is more protective of him. She has a closer relationship in a lot of ways with him than she does with my older brother and me. And my older brother and I have both moved away from M (town) and had our own lives. But my brother J never has and I don't think that is because of the diabetes. But he was the youngest, of course. But I know as a parent now if I had a child who was diabetic it would probably be harder to let them cut those apron strings and pull away as much as it would be for a child who did not have a medical problem like that. And she talked to me about the nights that she has laid awake worrying about him because of all the many ways the diabetes affected his life. Like sports. She worried about him playing basketball. He played basketball some and he played baseball some. Like I said my dad never encouraged him to mow the lawn or anything like that. So as a result I don't think he grew up and accepted responsibility quite as quickly as maybe he would have if he hadn't had this condition. Because I think more has been done for him. My brother and I both maybe babied him more than we would have and it might have caused him not to be as independent and stand on his own two feet as quickly as he would have. Like I said, I never felt, only felt compassion for my parents, because I knew how much they worried about him.

I: You said you feel your relationship between your younger brother and your mother is closer than it is between you and your mother. Can you talk a little more about how you feel about that?

R: There are times when, now that I have moved back to M (town) I think that I am more aware of it, it just seems like my brother can't make a decision about anything without calling my mom first, checking it out with her and seeing what she thinks. And part of that is that he has never been

away from M (town) but I also feel like he has just communicated with her more because like I said he never was allowed to, I probably should say encouraged, to stand on his own two feet very much. I have always thought that was because of the situation with the diabetes. It may not have been but that is what I always thought growing up. And there has been times as an adult when I thought it would have been good for him to leave M (town) for awhile and maybe stand on his own two feet a little bit more. Because now
I find that he feels almost like he has to have my mother's blessing or permission for every decision that he makes in life, whether if it is to sell his house and buy a new one, whether it is okay to sell his car and buy a new one or whatever. He almost feels like he has to have her permission. You know and here he is 38 years old. And you know sometimes I feel that her relationship with his children is closer than her relationship with my children. And there again I think it is because he is so dependent on her and she helps him more in every way than she does my older brother and, my older brother has no children and is not married. I, of course am married and have two children. She doesn't love my children any less and she would do just as much for them but she wants to be needed and dependent upon her. I don't depend on her like my younger brother does and I never have. I have always thought that is because of the situation with the disease. And it may or may not be. It may have been something else because we are very different in many ways. And I do resent that sometimes, and I resent how much she does for him and for his children. My mother is in poor health herself right now but she continues to do for him and that concerns me and that may have nothing to do with the diabetes. But I do think somehow that it is all related, it all stems back to when he was little and he was sick and she always had to do so much for him. I remember the transition when he started giving himself his own injections and that released her of a lot of the responsibility. That way he could go away for the day and he could spend the night with friends or whatever and he could take his insulin with him and give himself his own injections. But you know she had to always worry about his meals and now she still worries about his meals. She wonders if his wife is preparing his meals the way they should be prepared and that type of thing. I am sure that she doesn't always and they eat the fast food and things like that, which he never did when he was living at home. But I know it is hard for her as a parent to let go and just cut that off and not worry about that anymore. I think that is also related to the relationship that they have today and the way it compares to the relationship I have with her.

I: Earlier you stated that you were different, were you referring to your mother or brother?

R: My brother. My mother and I are alike. Probably more than I would like. (Laughs)

I: Talk more about that.

R: I see mother in myself a lot. J and I are different because I am proud of the fact that I am independent and I am proud of the fact, it was hard to leave home, but I left home and went to college and when I got married moved to A (town). I just now came back to M (town) and I have been away over 20 years. I was quite a mommy's girl, I realized that after I got married and moved away because it was devastating to me. But I realize it was really the best thing that could have happened to me. I think that has given me more insight into the relationship that my brother has had with my mother. It has never changed because it has never been challenged because he has never had to leave. And any problem he has ever had, every situation his life has ever had, he always run to my mother. He always run to my mother. He has been divorced and he is now remarried and through all that he ran to my mother. He moved back home in between marriages and that type of thing. I just think he is much more dependent on mother. Like I said my mother is very ill, she is not at the point of death. I know, I feel like my brother is kind of selfish with his relationship with our mom. And I feel if someday when we lose mother he will feel, I will feel the lost of a loved one, but not someone that I still need because of what she does for me. It will be just the lost of my mother and I feel J will feel that he doesn't even know where to begin. He doesn't even realize how much she still does for him. And I still think that goes back to the fact that he was a diabetic and just set the tone and she has just always done it for him. If he had moved away maybe that would have changed things. It is just like everything is still like it was when he was little and his mommy is still always there to take care of every kind of problem. He wants to be independent, he almost resents the fact, I think, sometimes that she is as much a part of his life and he would like to break free of that. But it is almost like he doesn't know how because she has been there for so long. And my mother and I are a lot alike and yet there are things in their relationship that I don't want to have in my relationship with my children. I don't want to feel as I am overbearing. Or that I am trying to run their lives. Or that I am trying to show my opinion about everything they do. She tries to do that with probably all of us, but J is more affected, because it is a great need he has for her helping him. Whereas my older brother and I we kind of listen to her and then we go and do

what we were going to do anyway. J almost feels guilty if he doesn't do it the way mother had said he should do it.

I: You see your brother as being very dependent on your mom.

R: Yes.

I: How does that make you feel?

R: I feel sorry for him now because he'll call and talk to me if there is something wrong and he'll say I am dreading to tell mom. Like they put their house on the market and he was afraid to tell mom because she just thinks that it is a really bad move. He'll call to get my opinion about what I think he should do about that or about whatever and I will tell him that he is 38 years old and he is a man and he and his wife need to make a decision about what they think is right. He should just explain it to mother politely. But I told him that he needs to realize that if she is giving him as much help as she is with his children and whatever else she is helping him with, I think she feels that earns her the right to make comments about what he does. In my situation I don't feel like I am dependent on mother for anything and I feel that it is my business what I decide to do. I know that mother worries about J more because she talks to me about how she is concerned with J because she thinks a lot of the decisions he makes are not the decisions he should have made. And I still think it is because she babied him so much when he was little which was not through any fault of her own. I think it was because of the diabetes. She just worried about him so much and always wanted to be there for him. And all these years way up to age 38 she has still continued to be there for him. And the relationship really hasn't change that much from when he was a little boy, the way I see it. And I feel sorry for both of them because I think they would both be happier if the relationship had grown a little more past the point of where he is. So I don't think she respects him as a man. I think she still looks at him as a child and I think he feels that mother still looks at him as a child. Whereas my older brother and I, I think she thinks we are grown up. I think that is the way it is. She won't hear this tape, will she? (Laughs). I am just kidding.
I: Can you talk more about how you and mom are the same?

R: Yes. My mom and I are both perfectionist and we both think things should be done the way we want them to be done. I hope I'm not, sometimes I'll make a comment to my husband and I'll immediately apologize and I'll say that sounds just like something my mom would say to my dad or I'll be critical of something the children have done, I'll say you

know you could have done so and so and I'll immediately catch myself and say this is a great idea. It is like I fight some of those things I feel that I want to say because it sounds like something she would say. But we also share some of the same taste. And all my life, even when I moved away from home, I remember when I would be out trying to make a selection about something for the home, an addition to my wardrobe or whatever, I would think, oh I wonder if mama would like this because we have always enjoyed shopping together. And our tastes in some ways are very different as far as colors and styles, but we always enjoyed selecting things together. We still enjoy going shopping together, that kind of thing. We are compatible. We are both very active in church and we talk about that together. We both enjoy the same kinds of books, the same kinds of movies. I feel that my mom is really proud of me and looks up to me and respects me. In a lot of ways I almost feel like she has me on a pedal stool and very proud of what I have accomplished. And I don't really feel that she feels that way with my brother. I think she feels that he never really found and reached his full potential as far as what he could have accomplished. I don't know if she feels that she bears any responsibility for that or maybe she does and maybe she doesn't. But we talk alike on the phone. When we answer the phone, people think I am mom and mom is me. We both enjoy music. I sing and I have entertained and performed a lot. My mom has been my biggest fan. She used to accompanied me a lot. I entered a pageant and voice competitions and things like that and she always made me very confident in my music. We share the same values. We kind of agree to disagree on certain issues. But we have a very, very close relationship. I can discuss most things with her but we do lock horns over the way she treats my daughter S and the way she treats my brother's children. She doesn't see the difference. I tried to explain it to her. I didn't have much success so I decided to just let it rest, but my brother even sees that.

I: What do you see as the difference?

R: I think she has spent more time with them, mainly with the younger child. She has raised the younger child before she started school and because both my brother and his wife work. She didn't spend as much time with my children because we have always lived away, so she just has a close relationship. So when we are all together she always thinks my children are trying to do something to the other children or not play fairly; or whenever there is a problem that involves my children, it is their fault. She buys more for the other children and spends more money on them. She pays the doctor bill. When she keeps them she takes them to the doctor and pays their bill. She buys clothes for them all

the time. That doesn't really bother me, I didn't make an issue of that. But my children sense a difference in the closeness that she feels with them and she feels with my children. My daughter has said several times that my mother doesn't like her. That she doesn't care about her. I think, that certainly is not true. But I think it is just because she is such a part of my brother's life and such a part of his family's life. To the point it is almost not natural to, the amount of time that they spend together. They are desperately dependent on my mother and on the other hand they really resent the fact that she wants to express an opinion about everything they do. But I think that she has earned the right to do that if she is going to have as much a part in their lives as she has. And whether not all this, I would be interested in knowing if anybody else has had this problem as they reached development. Because I have always wondered if all this does stems from the fact that he had the diabetes, and that started it back then. And they never broke off that protective shield that she always had woven around him wherever he went. On the church trips if he went she had to go. And I am sure I would probably feel the same way. I am sure it would be difficult to let your child go, knowing that they could face a problem with the diabetes.

I: The preferential treatment that your mother may have shown J, actually now extends to his children?

R: Yes. In this case it has. Mainly because when he married the woman he is married to now, this is his second wife, he and his first wife had no children and his first wife was an only child and very spoiled and had pretty much the same relationship with her mother that my brother has with his mother. I think that caused them a lot of problems. So then he married a woman who had a child and he adopted that child. But it is the younger one, they feel a difference in the way that child is treated and the way J's own child is treated. Even though he adopted the older one and that older child that is adopted feels the difference. And we joke about it in the family. My children and that older child are just kind of brushed off by the wayside as compared to my brother's natural child. She is the one that my mother has raised. She does the same thing with her, she is over protective of her because she raised her, she never went to day care. That child has had a problem adjusting to school now because she never related to any other children. She was always there with my mother. But it is just like it has been transferred from J to his daughter. And she is an asthmatic, a pretty severe asthmatic, so it is the same kind of protective. She has been rushed to the hospital in the middle of the night on a couple of occasions. They call my mother and she goes with them. So it is just, it is almost

like she is consumed with my brother and his family, particularly the younger girl. And I can't really say that I am jealous of that relationship because that is not what I would want, but I guess I resent the fact when I tried to explain it to mom, she doesn't understand it. She doesn't see my side of it. I think she just thinks I am being jealous or silly or something.

I: What are you feeling?

R: I feel that my children are being a little bit cheated because they don't have that relationship. And they don't have that relationship with the other side of the family either so they are missing all the way around. And then I feel sorry for my brother because of the situation he has got himself into. So I resent it as far as my mother is concerned and I don't really resent my brother so much because he apologizes for her all the time. And I just want to say it is about too late now because the little girl, if you could see what was happening way didn't you just pull her out and put her in day care. But I think he was just at a place that it was just too easy to just let mother do it. And mother was pretty adamant about being able to keep her. She even told my sister-in-law that she had two priorities, one was her home and the second was P (little girl). So that told us all what her priorities are. She doesn't know that I know that she said that. It may all be transferred, she may have transferred all her protective feelings from J now to his daughter. She is as close to her as she was to J. She really is. But mom and I are close and we have a very good relationship. I am just very careful now as far as what I say because I don't want to upset her. It is not worth it. And we will just kind of take what we can get as far as her relationship with my children. And I think they accept that, but I feel it is my mother's loss, because she does not have a relationship with my children that she could have. My daughter has cried on several occasions when we have been over there. She has even said she is not going back because if anybody ever gets into trouble, it's always my daughter. Nothing is ever said about my brother's children. That gets old after awhile. And it makes it really tense when we are all together.

I: Any of your mother's behavior remind you of when you and your brother were little?

R: I think I was pretty accepting of any preferential treatment that <u>he</u> received because I understood why he was getting it. And then when I went off to college, he was still in high school and he was the only child at home for quite some time. And he went to college for awhile, then he went to public broadcasting school for awhile. He stayed at

home all that time. I really don't remember having feelings like this so much when I was little and growing up. It seems to have gotten worse now that I am an adult. I may be wrong but maybe I, I think the main thing I felt when I was growing up was that I felt sorry for him and for my parents. I was always amazed that he never complained. My brother has never complained about his condition. He has never said "why do I have to have this?" He has handled that so amazingly well. And I have always been real surprised about that. But I don't remember feeling that so much when I lived at home.

I: The preferential treatment has gotten worse for you as an adult. Can you tell me more about that?

R: If he didn't have children and I was still just looking at as his relationship with my mother I don't think it was a healthy relationship. But I don't think it would bother me as much. Personally I would just think it wasn't my business. But I feel that J would be happy within himself if he could have somehow cut away, you know, like I said, grown up more standing on his two feet more. Maybe if I wasn't as happy in my marriage as I am and didn't feel that we are as successful as we think we are. I think we are doing well. If I felt like she had given him more help than she had given me and I had needed it as much then that might have bothered me. I really feel that she has tried to be fair as far as monetary gift giving. And I think she has always been there for all three of us when we need her, but I think she, my feeling of the preferential treatment is the treatment of the grandchildren. J and my relationship doesn't bother me. I do think my brother is very selfish. I think he is using her to his advantage at times when he knows he really shouldn't use her services because of her illnesses. I think maybe he is a more selfish person because he was given into so much. You know his, but I guess we all did that because we were all concerned about him, about his level. Like I said I still worry about him now. I worry how much damage this disease has done. I don't know how much damage this disease has done to his body. He has had it for so long. He has done well, taking his medication like he is suppose to. But in the long stretch you can't help but worry about what will be. His adopted daughter has scoliosis and she wears a back brace. So they have more than their share of problems, they really have. And I know all that is tied into the preferential treatment.

I: You said you worry about your brother even now. Can you talk more about that?

R: I think it makes me try to overlook the things that bother me because I think well he's treated this way because of his illness and I try to not let it bother me because at any time he could become severely ill. And I wouldn't want to do anything to damage our relationship or say anything that would hurt him in anyway. Because at anytime, I feel he is probably pretty fragile and he could suffer a sever illness at anytime. I really like my brother and enjoy his company, but like I said we are very different. Things that are important to us are different, family wise. Just the way we look at things we are very different. I really don't resent him. When I think about how I feel and our relationship and everything I think I just chalk it up to circumstances. And I think a lot of the circumstances stem from the fact that he was so protected when he was little because he was a diabetic. And a lot of that made him change and now it has just evolved into his adult life, and his marriage, and his family. And it will never change. It will always be that way. If he want something as long as my mother is alive, she is going to see to it that he and his family have everything that they need. And she would with all of us. But I just think she feels that there is a little more need there, from the time he was little. But I don't ever remember having those feelings of him being treated any differently before he had diabetes. I don't remember, but of course I was young. I do remember the way he was acting when she took him to the doctor when he was diagnosed with it. And I just have to wonder if he hadn't had that if it would have changed anything as far as his being able to take, if they hadn't been over protective, I wonder if he could have come a little further.

I: What is it like for you not to be able to express your true feelings because of his illness?

R: It bothers me. I would never, I would never talk to J about any of this. I talk to my husband about that and my husband and I talk about it a lot. We both have a lot of respect for my brother. Like I said because he has never complained about it. And I bet my brother has never stopped to think that maybe the reason that he and my mother are like that are because of his diabetes. Because he is real independent with it now, he never mentions, he never mentions his diabetes, he just quietly goes off to another room and takes his injections. I would never want to upset him or talk to him about any of these things that concerns me because it wouldn't be worth it to me, because then if he would get sick I wouldn't want to have to always remember that we had a knock down, drag out discussion about what was bothering me. He apologizes to me all the time. He used to call me after I had been home because he would see the difference in how mother treats his little girl. And I am

sure, he talks a lot of the fact that she has raised her. He knows she is over protective of her because of her asthma and she even gets on them that they are not taking care of her like they should. That they are not taking precautionary measures like they should. I am so much like my mother I might be doing the same thing. I don't know. I don't think I want to raise any of my children's children because I see what it does to the relationships of the other children, grandchildren. But I would never approach him about it or talk to him about it. He apologizes about it. I just say well I think that is just to be expected because mom spends so much more time with P. You have to expect that her relationship is going to be closer than it is with my children.

I: It must be difficult that you can't express your true feeling.

R: Yes. If I didn't have my husband to talk to, then I would probably explode. I talk to friends about it and my friends advise me to try and talk to my mother about it. But the one time I tried to talk to her about it sometime back, her blood pressure shot way up because she got so upset. She gets real defensive. She says she is always trying to be fair and she is always trying to treat all her children equally but no matter what she does, someone is upset. Just that kind of thing. She just started having a pity party. So I made up my mind right then and I was so scared, because her blood pressure went up. She had an appointment that afternoon anyway and it was on that same day that she found out that she has this kidney disease, which is treatable but not curable. And it is not getting any better. And it is really serious so I thought, gosh it is not worth it, you know, to bring up anything that is going to upset her. Same thing with J, I would not bring up anything with J because, but it hurts me, I have cried, I have laid awake at night feeling, I have always thought that I wasn't jealous of them but now I have about decided that I am jealous of the time she spends with them. There is not a day that goes by that, that J doesn't talk to mother on the phone. I don't talk to her everyday on the phone. When I didn't live here sometimes I would go two or three months without seeing her. I was used to that and she was used to that. But J, he can't make a decision, he can't do anything without calling her. She talks to him two or three times a day. If she has us over for dinner and she decides not to have J and his family, and she does not want me to tell them that we were over for dinner because she is afraid his feelings will be hurt because she did not ask them. I can tell that she does not always want me to know how much she is seeing them and how often she is seeing me. Because she probably is afraid, because when I see her she says I

haven't even seen J or T for two or three days. She always make a point of telling me that. So I think it is definitely in her mind that she is seeing him more than she is seeing me, or that she is doing more for them. Every once in awhile she'll give me a hundred dollar bill or two hundred dollars in my hands and tell me to go buy something for you kids. I know that she is doing that because she has been doing for them and handing over to them and that kind of thing. I can tell it is bothering her, so that is why she is willing to hand me this money. I just kind of laugh and say you don't need to do this. But it bothers me a lot and it's caused me a lot of tears and a lot of anxiety and a lot of frustration and like I said if I didn't have my husband and friends to discuss it with I would probably just be really, really, more upset and unhappy about it. My husband used to say every time we came home from a visit I was depressed. I think that was a lot of it. I don't think I have the relationship with mom that my brother has. Like I keep saying, I want to clarify that, I am not sure I want that kind of relationship. But I just want to feel that she knows me and that she knows my children and is a part of our lives. I wouldn't want her running my life, like I always felt she does with my brother. It may have been this way. Personality has a lot to do with it too. But I have always thought that it all started back to the time when he was diagnosed with diabetes and she became this overprotected mother as far as he is concerned. She says that she was over protective of all of us but I am sure she wasn't as over protective, because I was going on trips. When I was in elementary school I was going to camp through the church and she let me go. Of course she couldn't with J unless she went, because he needed the injections and special food.

I: You have talked about your relationship with J and your relationship with mom, can you talk about your relationship with dad?

R: Mainly we are very close, but I have to tell you that my dad, I think, is very put out about the time mother has put into her children. I think he feels like he has taken a back seat through the years. He and I are close but I don't talk to him as easily. If he is upset or has a concern about my brother and the amount of time he spends with my mom, then my dad will talk to me about it or he'll talk to my husband about it. There is a little resentment there in the amount of time that mother will think about J or talk about J or talks about his family or spends with his family. Because they are always there, and if they are not there then she is over their house. And I think that really gets on my dad's nerves. It kind of nags him at times and he has a really short fuse. My dad has a really short temper. He doesn't take things in stride as easily as some people do.

He gets kind of uptight and kind of a bundle of nerves. I think sometimes he's not as tolerant because he has just had it up to his ears with J and his family.

I: So you and your dad share some intolerance in regards to J getting preferential treatment.

R: Yes. My brother is not as close to my dad because I think he feels intimidated by my dad and I think he feel that my dad feels like he has never really grown up. Dad thinks that mom is babying him, because he'll say things like can't he do things for himself, can't he make a decision on his own, and that kind of thing. I don't feel like he feels that way with my older brother and me because we have made that adjustment. Yes, so there is definitely some resentment there on my dad's part. He verbalizes that, but he won't verbalize that much to my mom, he just lets it fester. Finally he shares it with my husband and me.

I: Both you and your dad hold in your true feelings, but are able to share them with your husband.

R: Yes. I never thought of it that way, but you know you have to have someone to talk about it, or I guess you'll explode.

I: You husband is very supportive.

R: Yes, he is very supportive and understanding.

I: Anything else you would like to add as far as what it is like to have a chronically ill sibling?

R: Only that I hope he will have a long and healthy life. I worry about him. I go about my business and everything. I could lay awake every night worrying about what is going to happen to him. He seems to be in good health now, but I think he does try to take good care of himself but I worry about him. And I would do anything for him. And I think he has handled his condition well, probably better than I would. And I feel sorry for him sometimes. If he hadn't had this illness, if maybe he would have been able to grow up a little bit more, been a little bit more happy of himself as a person. Because I think that he really has a lot of doubts within himself, and I think he is not the person he would have been if he had not had this serious illness. A over protective and over bearing mother. And then the fact that he was the youngest one too, I am sure played a part in it as well. Maybe if he had diabetes and he had been the oldest one, that would have compensated for the fact that she had two younger ones coming up behind him and that would have taken some of the load off of him. But

I am proud of him. I am proud of my brother and I love him. We talk about a lot of things. I feel that he looks up to me and that he enjoys talking to me about things before he talks to my mother about it because he uses me as a sounding board. I think he and his wife both resent my older brother and me because I think they feel that my mom looks up to both of us. They kind of feel like we have accomplished a little bit more. I think that they resent that sometimes. I think there is some resentment on both sides for different reasons. The resentment I feel is based totally on different things then the resentment they feel. I think my brother and I are close, but sometimes I wonder what he says about me when I am not around, you know that kind of thing.

I: You feel he says something different when you are not around?

R: Yes, maybe. I think he really loves me. Sometimes I wonder if he thinks maybe that I have some kind of attitude or something. I don't know. I know that they are trying to sell their house and get a new one. They always say that they could never afford what you have, but he had the same opportunity to go to college as I did and he chose not to go. My older brother and I both went and we both married professional people. My older brother is divorced now but he is very successful in his position. He does very well for himself. I married a college graduate and we are both educated people and J didn't go to college and he married someone that didn't go to college. That was his decision and his choice and he was willing to settle for less. We enjoy being together. They were over here last week-end and we had a good time. Both my brothers were here and we had a good time. We just enjoyed each others company. We are all very, very close and we are all very different and we do have some of these feelings that I am sure that other families have. I do think that a lot of it stems from the fact that he was a diabetic when he was little.

I: Anything else you would like to say before we end today?

R: No. I feel bless that I don't have a child with a serious illness. I do think that it is important for the whole length of the relationship to try to, try to understand how everybody feels and what the impact is on everybody. I remember when my mother used to talk to us about it, but it usually was from J's viewpoint. It was like don't eat that in front of J. Don't do that here, that will make J mad, that kind of thing. And at the time I don't remember it bothering me very much at all, but I think it would have been real important to see how it is making all the other children feel too. The fact that he is not the only child in the family, they are having to give up

certain things and be careful of certain things because of the illness that the one has. I never felt, when I was growing up, I never felt. . . he got preferential treatment, but I understood it. And I didn't have a problem with it but I was 3 years older. If I had been closer to his age it might have bothered me more. I think I was so grateful I didn't have to have the shots and that I could eat what I wanted to, I think that is what balanced the scales. I think that is way I didn't feel like I was being neglected or anything like that. I felt fortunate that I didn't have to put up with what he had to put up with.

I: You said your mom would describe it from J's viewpoint, can you talk more about that?

R: Well my viewpoint was that I was willing to do that for J and I don't remember ever trying to have a snack in front of him. We all changed what we had for snacks. We tried to have things he could have. I think there were times I would wish that we could have a dessert or something like that. I felt that was a small price to pay, to give up something like that for him. And I sure didn't want to tempt him to eat something he was not suppose to eat because he was always really good about that. She would say it is not good for J to have this so you shouldn't have it. She would probably say you wouldn't want to do anything that would hurt J or that would tempt J to eat something that he shouldn't eat with you. I would say "No". And I am sure she would find ways to get me something when J was not there. It was always to help me to understand J, how it would make J feel if he saw me eating this or having that. I can remember hiding in the kitchen eating things. She would make him chocolate pudding that he could eat and then make us regular pudding. That wasn't as big a deal as I am making it sound now, but it was hard when I was little to do without something that I would like to have. She naturally felt more sorry for him because of having the diabetes and having to have the shots.

I: So when she would tell you that you can't eat this because J can't have it, what were you feeling?

R: I probably thought I wish J could have it so I could have it. I am sure that is what I felt sometimes but I felt sorry for him.

I: Thank you very much for your time today.

VITA

Marilyn Elizabeth Smith was born in Pittsburgh, Pennsylvania on October 22, 1946. She attended elementary school in Sharpsburg, Pennsylvania and high school in Denville, New Jersey. She received a diploma in nursing from St Francis Hospital School of Nursing, Pittsburgh, Pennsylvania, in June, 1968. The Bachelor of Science in Nursing degree was awarded in May, 1971 from Duquesne University. In May, 1977, Marilyn received a Masters of Science in Medical-Surgical Nursing from The University of Michigan, Ann Arbor, Michigan. In December, 1991, Marilyn received a Masters of Science in Rehabilitation Counseling from West Virginia University, Morgantown, West Virginia.

Marilyn's nursing career has included working with clients of all ages in various settings. She has also worked in nursing education.

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