CHILD REARING PRACTICES: CHILD WITH CHRONIC

ILLNESS AND WELL SIBLING

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TEXAS WOMMOND DUMINISTEM MARARY

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Dedicated to

my mother

Carolyn Anderson King

who taught me to be skeptical

and in memory of

my father

William Anson King

who thought curiosity

was a good thing

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CHAPTER 1

INTRODUCTION

Chronic illness in children affects the existence of not only the child with the illness but also the family of the child and the society within which the ill child lives. Chronic illness interacts with family and societal variables and produces long term effects on the child, his family, and society. The child with chronic illness needs to grow into a functioning adult. To accomplish this goal, the child must have certain educational and social experiences. Without these experiences it is possible that as an adult he will not contribute to society and may be economically dependent on his family and society. Parents are responsible for seeing that the child receives these experiences as well as the treatment for his disease.

It is reasonable to assume that the functions of parents of healthy children and parents of children with chronic illness differ from each other in at least one major aspect. Parents of children with chronic illness must maintain a treatment regimen. When goals of development are in conflict with goals of treatment, the parent must decide which goals assume priority. Parents learn to

make these decisions largely on the basis of trial and error, for rarely is there an available role model. Parents must also limit the child's behavior in such a way that the child will conform to the treatment regimen enough to control his disease process yet be free enough to try new experiences. A goal of parenting is to produce an adult who will be able to function independently in society.

The child with chronic illness differs from the child with acute illness and the adult with chronic illness in several ways. Kassebaum and Baumann (1965) felt that Parson's concept of the sick role must be modified to be applied to persons with chronic illness. Role expectations based on temporary illness do not apply to the person with chronic illness. Many persons with chronic illness are ambulatory so that a person's incapacity to fulfill certain role requirements may be temporary rather than permanent. The assumption that the sick role is always the dominant role may be unwarranted in chronic illness. Social norms requiring permissive treatment of the sick may be altered for the chronically ill.

Ambiguity exists when the child with chronic illness is compared to the adult with chronic illness. The sick role is divided particularly with regard to interactions with the health care delivery system. The child has the

symptoms, but parents must deal with health professionals and carry out treatments. Meadows (1968) feels that the sick role is modified for the child with chronic illness. Sick role implies that the patient is willing to cooperate with the physician. Attempts to recover release the patient from other role responsibilities. Meadows (1968) feels that the parent of the child with chronic illness is the patient surrogate. The parent must carry on the business of recovery, but he is not released from other role responsibilities. Treatment greatly adds to the child-rearing responsibilities.

The role of the parent of a child with chronic illness can be a difficult one. Logically, one would assume that there are differences in child-rearing practices toward well children as compared to children with chronic illness. Although case studies report that parents rear children with chronic illness differently, surprisingly little experimental evidence of differences exist. Relatively few studies with experimental or quasi-experimental designs have been attempted. Studies that have been attempted, particularly the case studies, have sought to apply a pathological model to these parents, making parents of children with chronic illness "abnormal" by definition. Studies of parents of children with chronic illness are often carried

out in medical centers where larger populations are available. These settings tend to have a higher proportion of pathology of all kinds which limit the generalizibility of the results.

Problem of Study

The study question is stated as follows: What are the differences in child-rearing practices of fathers and mothers toward a child with chronic illness and his well sibling?

Justification of Problem

Chronic illness affects the lives of many children in the United States today and is a significant health problem of children. Society can expect children with chronic illness to grow to adulthood, for many of these diseases are not immediately life threatening. Much research has been done to discover the exact nature of physiologic defects and the treatment of its physiological manifestations. There is a dearth of information about the affect of the child's social environment on physiological outcomes. Child development specialists as well as persons involved in giving care to children with chronic illnesses and handicapping conditions indicate that the mutual effects of chronic illness and family functioning are in need of study (Dinnage, 1970, Pringle, 1974).

Nursing has held that a major part of its role is aiding the client's move toward self-care. Parents of the ill child have face-to-face relationships with the health care system. Nurses will be working with parents to enable children to grow into responsible adults. The knowledge base to accomplish this goal is small and poorly documented by empirical data. Longitudinal studies which will define those factors which influence a child's movement toward self-care are needed. Short term studies which demonstrate the relationship between self-care and control of the disease process are also needed. Prior to treatment, however, characteristics of the child's environment need to be identified. A major part of the child's environment is his parents. The child responds to many environmental cues from parents. The American Nurses' Association (1976) listed the following as a resource priority which needs further study: "Studies of adaptation to chronic illness and the development of self-care systems and group care systems" (p. 2).

Parents of children with chronic illness are asking for guidance. Meadows (1968), in her study of deaf children, discussed parent's expressed need for an alliance with a knowledgeable lay person who has successfully dealt with the situation. Voysey (1972) stressed the importance which

parents attached to sources of information for and by parents of the chronically ill and to the expressed need for parent associations. In a report of a study of 21 children with cerebral palsy in Shopshire, England, 69% of the parents expressed the need for some authority to whom they could turn for advice. This study would give parents base line information about child-rearing practices in families where there is a child with chronic illness (Dinnage, 1970).

The nursing profession expresses its goal as helping the client move toward self-care. The nurse's role includes documenting those factors, including child-rearing practices, which influence a client's movement toward self-care. Parents of children with chronic illness are asking for help as they attempt to deal with the problems of rearing a child with chronic illness. The science of nursing needs to gather the information necessary to give parents the help they need and children the guidance they need to become adults capable of self-care.

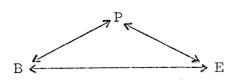
Theoretical Framework

Bandura (1977) has developed a theory which explains human behavior as a function of social learning. He has combined the strengths of both psychoanalytic and behavioral theory. Social learning theory will be used as a structure

for this study because it has an interactionist view of child-rearing. The discussion of social learning theory will be divided into the following parts: View of man and his environment, the process of social learning, and application of social learning to child-rearing of children with chronic illness.

View of Man and His Environment

Reciprocal determinism is the concept which explains the relationship between man and his environment (Bandura, 1977). This concept implies that "behavior, other personal factors and environmental factors all operate as interlocking determinants of each other" (p. 204). <u>Reciprocal</u> determinism is symbolized as follows:



B is defined as behavior, P is defined as personality factors, and E is defined as environment. There is a two-way regulating system between these components. The individual appears as object or agent of control depending on which side of the process one chooses to study.

Bandura (1977) feels that for purposes of study, one can separate parts. Behavior, personality, environment, and

their interaction can be studied separately. The effects of environment on behavior can be studied. This would be called environmental determinism. Environmental determinism is symbolized as follows: B = [f (E)]. An investigator can study the effects of personality factors on behavior and this would be called personal determinism. <u>Personal</u> <u>determinism</u> is symbolized as follows: B = [f (P)]. Reciprocal determinism is the two-way control which operates in every day life. The same event can operate as a stimulus, a response, or an environmental reinforcer depending on the place in the sequence of events which the analysis begins.

Numerous personality factors are involved in this concept of man. Many of these personality factors are the result of the interaction of man and his environment. Role is one of the many personality factors. Inherent in the concept of role are prescriptions designating behavior as the individual carries out certain functions in society. Role also determines acceptable interactions with other individuals in society. A role allows a person to predict consequences of behavior over time; therefore, it serves as a structuring influence over reciprocal interactions over time. A person's concept of role can act as a reinforcer of behavior (Bandura, 1977).

Bandura (1977) differentiates between the potential environment of man and the created environment. The potential environment of a person is fixed and the same for everyone. A person also makes his own environment which is individual. A person's behavior can create environmental conditions as well as regulate the impact of the environment.

Behavior of man is not seen as stagnant. Because of the counter influences of personality and environmental factors behavior undergoes continual readjustment. Personality and environment also undergo continual readjustment or repatterning (Bandura, 1977).

The Process of Social Learning

Behavior, particularly complex patterns of behavior, is learned. Stimulus-response learning can explain behavior in simple situations where there is a lot of practice time available. Stimulus-response cannot account for the fact that man can learn complex patterns of behavior where little practice time is available. Bandura (1977) feels that much behavior is learned by contact with a model. The model can be behavior of another individual, a picture or a representation of the phenomenon to be modeled, or a verbal explanation.

Modeling can be described in terms of its scope and its modes. The scope of modeling is how the individual learns a pattern of behavior and includes both mimicking an activity and the learning of rules and principles. The individual learns the following modes of behavior from models: self-control patterns, self-evaluation responses, social behavior, including moral reasoning, standards of self-reinforcement, understanding of symbols, and value preferences. Modeling can effect behavior in the following ways: disinhibition, response facilitations, and stimulus enhancement.

The learning process is considered to have six parts (see Figure 1). The modeled event occurs. The observer must attend to the modeled event. The factors which influence whether or not the observer will attend the modeled stimuli can be divided into the following two categories: characteristics of the modeling stimuli and observer characteristics. Characteristics of the modeling stimuli which affect attending are listed as follows: distinctiveness of the stimuli, affective valence of the stimuli, complexity of the stimuli, prevalence of the stimuli, and functional value. Observer characteristics which affect attending the stimuli are listed as follows: sensory characteristics, arousal level, perceptual set, and past

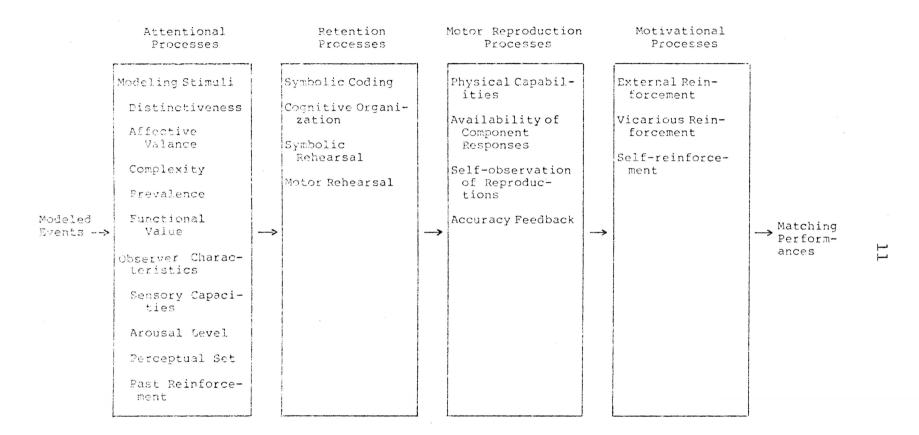


Figure 1. Social learning theory (Bandura, 1977).

reinforcement. Once the observer attends the modeled event, this event has to go through the following processes: symbolic coding, cognitive organization, symbolic rehearsal, and motor rehearsal. The following factors influence the observer's ability to reproduce the modeled event: the physical capabilities of the individual, the availability of component responses, self-observation of reproduction, and accuracy of feedback. The observer is further influenced by the following motivational processes: external reinforcement, vicarious reinforcement, and selfreinforcement.

Application of Social Learning to Child-Rearing of Children with Chronic Illness

Parenthood is considered to be a position in a social structure or a role to social learning theories. Parenting is a role to be modeled. This position is socially tied to other positions and groups, e.g., parent of the opposite sex, child, teacher, neighbor, pediatrician, etc. (Handel, 1970). The practices necessary to rear children are complex in nature and are shaped by many segments of the society which compose the environment of the parents. The segments include the ethnic group, the religion, and the occupational group. All of these segments are seen as evolutionary, therefore changing, and parents can change religious and occupational affiliations. This study will take an environmental determinist view, B = [f (E)]. Child-rearing practices are a function of the environment within which they exist. The environment of the parent of the child with chronic illness is different from the environment of the parent of the well sibling. The community support systems are different; the child is different. Models for child-rearing practices of "well" children are a part of the community support system.

Many models exist in society; however, individuals differ in the degrees to which they respond to modeling. A modeling cue is powerful when it is associated with particular response outcomes which act as rewards to the individual. Those factors associated with the ability of a model to elicit a response are listed as follows: response consequences associated with the matching behavior, characteristics of the model, and attributes of the observer (Bandura, 1977).

Response consequences of the behavior are the most powerful predictor of whether or not a model will be accepted. The behavior must have functional value to the observer, the parent. The other factors such as characteristics of the model or attributes of the observer operate only when the situation is unknown or the response consequences are unknown.

The major characteristic of the model which enhances the cueing function is status. High status, competence, and power are effective in stimulating behavior in another individual. The model cannot be of such high status that the observer feels that it is impossible to emulate the behavior. The model must be in some sense apeer. The effects of the model do generalize from one area of behavior to another. Some of the behaviors will have nothing to do with the response outcome desired. The status of the model is the most important factor in predicting whether or not a behavior will be modeled when the response outcome is unknown or unclear (Bandura, 1977).

There are two situations where the characteristics of the model are important in predicting the people who will be most responsive to modeling. In unfamiliar situations where unfamiliar models are used and the response consequences have little or no functional value for the observer, persons who lack confidence and self-esteem, who are dependent, and who have been regarded for imitative behavior in the past, are most likely to respond to modeling influences. Perceptive, confident people will more readily respond to idealized models whose behavior has a high degree of functional value. These more venturesome people are apt to derive greater benefit from the observation of exemplary. models.

Assumptions

The following are the assumptions of the study: 1. A mutual interaction exists between man and his environment.

2. An individual's behavior is affected by other individuals in his environment.

3. The parent of the child with chronic illness perceives behaviors necessary to carry out the parent role as different from the behaviors necessary to carry out the role of parent of the well child.

4. Fathers and mothers perceive their roles differently, behave differently, and have different models for parenting behavior.

5. The Child-Rearing Practices Questionnaire measures variables which are representative of actual child-rearing practices of parents.

6. The sample is characteristic of the population from which it was drawn.

Hypothesis

The research hypothesis of the study stated globally is as follows: There will be a significant difference in mothers' scores and fathers' scores for children with chronic illness and their well siblings on the following four variables: 1. Use of punishment vs. reason

2. Promotion of independence vs. dependence

3. Level of rules of behavior

4. Amount of spouse involvement

The independent variables will be sex of the parent and health status of the child (see Figure 2). The dependent variables are listed as follows:

1. Use of punishment vs. reason

2. Promotion of independence vs. dependence

3. Levels of rules of behavior

4. Amount of spouse involvement

Definition of Terms

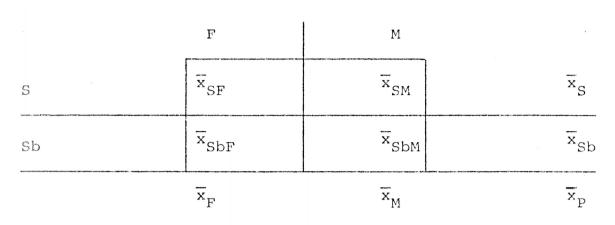
The following definitions of terms are considered important to the understanding of the study.

<u>Chronic Illness</u>. An illness where the pathological process is of a long duration.

Disability. The immediate, direct manifestation of the disease or trauma as it affects behavior (Pless & Pinkerton, 1975).

Handicap. The consequence of a disability in relation to specific goal related activities (Pless & Pinkerton, 1975).

Model. A person or representation which an individual chooses to emulate.



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Key: F = Father M = Mother S = Child with chronic illness Sb = Sibling of child with chronic illness or disability P = Combined child-rearing

Figure 2. Diagram of independent variables.

<u>Parent</u>. A father or a mother (Daves, 1976). These people can be either natural or adoptive but they must have legal responsibility for the child.

Role. "The term reflects at least three rather different conceptualizations."

1. The prescribed role "consists of the system of expectations which exist in the social world surrounding the occupant of a position-expectations regarding his behavior toward occupants of some other position."

2. The subjective role "consists of those specific expectations the occupant of a position perceives as applicable to his own behavior when he interacts with the occupants of some other position." 3. The enacted role "consists of those specific expectations the occupant of a position when he interacts with the occupants of some other position" (Daves, 1976, p. 143).

Sibling. "An offspring of one or more of the same parents" (Duetsch & Krauss, 1965).

Limitations

The study was subject to the following limitations:

1. Children in the study were 4 to 13 years of age.

2. The child-rearing practices variables were limited to those measured by the child-rearing practices questionnaire.

3. There was no control for amount of hospitalization.

4. No attempt was made to control for socioeconomic or sociocultural groups.

5. The independent variables were non-manipulated.

6. No distinction was made regarding types of chronic illness.

7. Siblings in the family not included in the study were not considered.

 The number of years since diagnosis was not kept constant.

9. No evaluation was made of the severity of illness and disability.

Summary

Parents of children with chronic illness are asking for quidance as they attempt to raise their child with chronic illness (Meadows, 1968; Voysey, 1972). They are asking for help from knowledgeable lay people to function as models for behavior even when other children have been successfully parented. Parents must see their role as parent of a child with chronic illness as different from parents of children without chronic illness. The models of behavior which parents have used in rearing their non-ill children are not sufficient when a child with chronic illness shares the sick role with the parent. These parents have more role obligations and less social support to carry out these obligations (Meadows, 1968). The role of father of the child with chronic illness is an unknown phenomena. How do fathers perceive their role; who do they use as models? Only one study reviewed considered the father as a variable. It is possible that fathers would choose models of the same sex; if so, their child-rearing practices would be different from mothers.

This study is designed to answer questions about childrearing practices in families where there is a child with chronic illness. The child-rearing variables which were studied were chosen and are listed in this chapter in the

hypothesis statement. The assumptions of the study and a definition of terms are listed in the hope of clarifying the reader's understanding of the problem studied.

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this chapter is to review what is presently known about the child-rearing practices in families where there is a child with chronic illness. The chapter will be divided into the following sections: The evolution of the research problem, and review of related literature.

Evolution of the Research Problem

Studies of importance in the field of child-rearing of children with chronic illness had, as their focus, the physical and emotional adaptation of that child to his illness and disability. The majority of the studies most frequently cited have dealt with children with severe disabilities.

The study of adaptation to long term illness was a part of a discipline called somatopsychology. Somatopsychology studied mind-body relationships and how they interacted with the environment over time, in an attempt to identify causal relationships. Child-rearing practices were seen as affecting the mind of the child, e.g., his self-esteem, and his identity. Researchers had attempted

to collect data to support the idea that child-rearing practices were seen as affecting the mind of the child, or caused increased physical disability as with asthma and rheumatoid arthritis. The data which supported this attitude were very limited.

Much difficulty had been encountered in gaining general acceptance of the causal relationships that had been proposed because it became difficult to identify the independent and the dependent variables. Did chronic illness affect family life or does family life affect chronic illness (Korsh, 1976). Often studies with experimental designs could not be done for ethical reasons.

Many difficulties were found in obtaining human populations to do studies with experimental designs; therefore, many studies have been descriptive correlational studies. In research on problems other than mind-body relationships, a high correlation was taken as evidence that there was a good chance that a strong, perhaps causal, relationship existed between the variables. With mind-body research, high correlations almost always implied a third variable which had a causal relationship to the criterion variable. One could probably obtain a positive correlation between body weight and math ability. Men weigh more than women, and men scored higher on math ability tests. Math ability

did not cause weight gain or vice versa. Moderate correlations which were statistically significant were open to a wide variety of interpretations. Often the alternate hypotheses could not be evaluated empirically (Shontz, 1975).

When attempts were made to demonstrate causal relationships, many difficulties were encountered. One characteristic of mind-body studies was that there was generally a large variation around the criterion variable implying that the effects of the independent variable were not homogeneous. Application of the research was difficult to justify and the clinical usefulness of the data was limited. When one was attempting to look at what caused behavior in the chronically ill, it was rare when the researcher separated variation due to the environment from variation due to interaction of these factors (Shontz, 1975).

There were six arguments which were used to account for the moderate correlations and high degrees of variability. It was argued that there were uncontrolled factors which influenced the wide degree of variability. Little effort was made to work with this problem because of ethical reasons, lack of knowledge, or lack of interest (Shontz, 1975). The complexity of interaction of the variables was the major justification for the use of the

case study approach. A second argument used for explaining the results of studies was the inadequacy of measurements (Pless & Pinkerton, 1975). Little effort had been made to refine the instrumentation (Shontz, 1975).

Where causal relationships had been hypothesized and not confirmed, other arguments had been used. One argument was that the relationships were facilitative, not causal (Shontz, 1975). A certain person was predisposed to a certain mode of behavior either because of genetic or environmental influences. The chronic illness potentiated this behavior. This principle could work in reverse. A person might have had a predisposition for a disease which was facilitated by this environment.

Mediation was another argument used. This argument stated that mind-body relationships existed, but they were mediated by one or more other variables. The relationship would exist only when one or more other variables came between the other cause-effect relationships. Multiple causation was another argument used. This argument stated that two factors, disease and another variable, were needed to produce high correlations. Third factor influence was another argument used. No causal mind-body relationship existed; however, both of these variables caused or were caused by a third variable (Shontz, 1975). Shontz (1975)

stated that there was no convincing evidence to support the fact that there was a direct causal relationship between personality and physical illness and disability. Yet, research continued in an attempt to identify those personality factors which supported successful adaptation.

Minde, Hackett, Killow, and Silver (1972) had identified research problems involved in identifying factors which influence the child's adaptation. Much research tended to see the problem as static. Things that were important in the adaptation of a two year old would be important in the adaptation of the adolescent: once adapted, always adapted. There had been an overemphasis on the mother-child dyad as a factor influencing adaptation to the exclusion of other environmental influences such as the family or the community. The family, when it was considered, was often considered as static, not developmental. Family variables were not considered to change over time.

Many problems in obtaining objective measurements of the variables were reported. Often times retrospective accounts of the variables were measured as with the interview studies. Much observer bias was injected into the data. Poor operational definitions of the variables in question were common, so the conclusion lacked clarity

(Minde et.al., 1972). Often studies looked at the family or society's reaction to the deviant portions of the child and not the child as a whole. This attitude limited conclusions which could be drawn (Minde et al., 1972).

Review of Related Literature

The purpose of this portion of the paper was to identify those factors which affected adaptation to long term illness. The research literature was directed toward adaptation of the child; however, child-rearing factors are highlighted whenever possible. This section is divided into the following three major parts: illness factors, factors inherent in the child, and factors inherent in the child's environment.

Factors Inherent in the Illness

The outcome of the disease and the disability which it produced were two major factors which influenced adaptation. The symptoms which led to diagnosis were also felt to be important in that they often affected how much rehabilitation could take place. The diagnosis process itself was thought to influence the parent's reaction to the child and to the illness. The illness factors were seen as affecting the environment within which the child developed. The illness and its symptoms were thought to

affect either the child's attitude toward himself or other persons' attitudes toward him. There was no evidence that illness, child, and environmental factors were independent.

The visibility of the disease influenced both the child's perception of himself and other persons' evaluation of him. Richardson, Hastorf, Goodman, and Dornbush (1961) compared self-description of children, ages 9-11, with various chronic illnesses and disabilities with a non-ill control group. These data were collected by nondirected interviews. Children were interviewed while attending summer camp. Boys and girls in the experimental group had more negative statements about themselves. Society placed less value on the person with the observable disability. Richardson et al. (1961) asked children and adults to rank order pictures of children with various disabilities. In general, the order of preference was: (1) the child with no visible handicap, (2) the child with crutches and a brace, (3) the child in a wheel chair, (4) the child with a left hand amputation, (5) the child with facial disfigurement, and (6) the obese child.

The illness and its symptoms and treatment were thought to limit the experiences of the child. Neurophysiologic body image was the frame of reference by which an individual interacted with his environment (Watson & Johnson, 1958).

Shere and Kastenbaum (1966) studied mothers of children with cerebral palsy and found that these mothers played less with their cerebral palsied child as compared to their other children. Blindness and deafness caused obvious sensory deprivation in the child, particularly when the condition was present from birth. Communication was often a problem particularly for deaf children. Blindness and deafness were often associated with other perceptual problems (Pless & Pinkerton, 1975). Cowen, Bach, Hauser, and Rappaport (1961) summarized their longitudinal study of the adjustment of blind children as follows:

Blindness from birth may have less consequences for the child's own self concept, once formed, but children born blind tend to be more affected by other people's attitude toward them . . There was overall acceptance of the emphasis placed on good intelligence as a key factor to successful adjustment. (p. 116)

Cowen et al. (1961) implied that the sensory deficit could be overcome if the child had better than average intelligence. Williams (1970) found a higher incidence of psychiatric diagnoses in deaf children as compared to a normal population. Blindisms and deafisms were additional observable signs which stigmatized the child as different. Voysey (1972), in her study of parents of ill and disabled children, found that parents would avoid placing their children in situations which made them appear abnormal.

Juenker (1976) felt that an illness which was observable was easier to integrate into a total body image than one whose symptoms were not observable. Though no experimental evidence for this opinion exists, she stated that children with orthopedic problems adjusted more positively to their illness than those with diabetes. She felt that orthopedic problems were more tangible. The child could see the evidence of the disorder and how it was to be treated. The observability of the condition discouraged fantasy. The child who had juvenile diabetes or asthma could not see what was wrong with him. Medical treatment was given for no observable reason. Fantasy seemed inevitable. Jeunker assumed one age group for children. Her point of view would have had a greater probability for being valid for children who had been in the contrete operations stage of cognitive development.

There were some symptoms which inhibited establishing a material bonding. McCollum and Gibson (1970) compared the parenting of children with cystic fibrosis with their non-ill sibling. The feeding disturbances which were established in the prediagnostic stage continued long after the dietary problems were controlled with pancreatic enzyme, and affected child-rearing.

Factors Inherent in the Child

Mattsson (1972) made the concept of adaptation explicit to the individual with long-term illness. He defined coping behaviors as all adaptational techniques, developed by individuals to master a major psychologic threat and its attendant negative feelings in order to achieve one's personal goals. Coping behaviors included cognitive functions such as memory, speech, judgment and reality testing, motor activity, and psychologic defenses. Mattsson (1972) felt that most people with chronic illnesses did adapt. The criteria for adaptation were listed as follows: (a) the person was able to function at home, at school, and with peers; (b) dependence was age appropriate; and (c) the assuming of self-care responsibility was age appropriate. The characteristics of the person who had adapted to long-term illness were listed as follows: (a) cognitive flexibility, (b) compensatory physical activity, and (c) appropriate release and control of emotions.

Factors which were inherent in the child were implicated in adaptation and listed as follows: age of onset of symptoms, the development of the child, and age of the child at diagnosis. The age of onset of the symptoms was seen as affecting many factors implicated as affecting adaptation.

Children who had illnesses or anomalies which were diagnosed at birth were often separated from their mothers. Infants were particularly susceptible to the negative effect of separation. Kennel and Klaus (1976) studied the parents of premature infants. The parents were grouped into two groups. Those who visited more than three times in 2 weeks were in one group, while those who visited less than three times in 2 weeks were in another group. Disorders of mothering, including abandonment, battering, failure-tothrive, and placement in foster care were compared. The mother who visited less than three times in 2 weeks had a great number of disorders of mothering. This number was significant, p < .001. Hospitalization, casting, and surgery were often associated with a lack of environmental stimuli which an infant needed for cognitive and motor development (Kessler, 1966).

Some researchers felt that there were periods in a child's psychosocial development where he had to confront his illness. Starting to school was one such period. Minde et al. (1972) studied 41 families which had had children with handicaps who had been sent to a special school. They felt that development of the handicapped child between 5 and 9 was highlighted by the following: (a) cognitive realization of the stigma triggered by loss

of outside peer group and exposure to other children with handicaps, and (b) depression. He felt that this depression was the first step which the child had to take to see himself in totality, his normal parts as well as his disability (Minde et al., 1972).

The adolescent period seemed to be another time where the individual had to deal with his illness. Stearns (1959) pointed out that three out of five adolescents who committed suicide in a metropolitan area in a 9-year period had been diabetic. He felt that self-destructive behavior in the adolescent with diabetes was conscious. Freeman (1970) compared adolescents with cerebral palsy with their sibling. He found that the siblings had more behavioral and school problems. He felt that the solution of the problems of the adolescents in the person with cerebral palsy was related to the following: (a) body image which is related to success or failure in using the body; (b) the meaning which the adolescent attached to the attitude of others toward him; (c) the prolonged period of dependency; (d) less opportunity to master unpleasant situations; (e) minimal opportunity for play, exploration, and competition; and (f) the fact that he was protected from full confrontation with his limitation. The physical changes of adolescence had to be dealt with. The adolescent had to give up the

fantasy of cure. As peers became more aware of the defect, the adolescent with cerebral palsy was left out of social experiences. Certain activities which conferred social status, such as driving a car, were restricted to many adolescents with cerebral palsy. The adolescent with a handicap had to deal with sexual maturity. Freeman (1970) had no explanation for the increase in problems of the siblings.

The age of the child at onset logically should have influenced the child's adaptation. The earlier the disease was discovered, the more pervasive and profound were the effects on the child's life (Kessler, 1966). No empirical evidence for such a belief existed. If the child contracted the disease or injury at school age or later, he had developed a repertoire of defense mechanisms to deal with stress. He had had a period of life that his bodily integrity had been intact. These strengths of personality could be used as he dealt with the changes in his body and his life. However, one could argue that an acute change in body integrity produced more stress and grief than a gradual realization of the meaning of disability.

Factors Inherent in the Environment

Siegleman, Block, Block, and Von der Lippe (1970) studied a concept called optimal adjustment which was

defined as optimal psychological functioning. This concept was similar to the concept of adaptation. Siegelman et al. (1970) found that child-rearing and environmental factors were associated with high optimum adjustment. This portion of the paper will deal with the family and social characteristics which were associated with adaptation and will be divided into the following parts: the sick role, the chronically ill child, and parents of the chronically ill child. The sick role as it related to chronic illness had been discussed in Chapter 1 (see page 2).

The Sick Role

Parsons's (1972) concept of the sick role was useful in looking at environmental influences on adaptation. Parsons considered the sick role to be an example of social deviance and as such considered by society as bad, or at least, less than good. The sick role was a social status conferred on a person by society. A person accepted and engaged in sick role behaviors defined as those behaviors a person engaged in for the purpose of getting well. Parsons (1972) defined the following specific features of the role of the sick person:

1. The incapacity is interpreted as beyond his powers to overcome by the process of decision-making alone; in this sense he cannot be "held responsible" for the the incapacity.

2. Incapacity defined as illness is interpreted as a legitimate basis for the exemption of the sick individual, to varying degrees, in varying ways and for varying periods according to the nature of the illness, from his normal role and task obligations.
3. To be ill is thus to be in a partially and conditionally legitimate state.
4. The sick person and those responsible for his welfare, above all, members of the family, have an obligation to seek competent help and to cooperate with competent agencies in their attempts to help him get well. (p. 117)

Kassebaum and Baumann (1972) had expanded Parsons' ideas somewhat. Upon being defined by society as sick, the individual was isolated from certain parts of society. This isolation was to prevent the sick person from attempting a role obligation which he was incapable of performing, thereby protecting both the individual and society. The sick person was not required to live by the same norms as the well population, particularly those who value independent achievement. He was exempt from the obligation and strain of trying hard to achieve. He was permitted to indulge his dependency needs and he was allowed to enjoy various secondary gains. However, he had to see his state as bad and work, e.g., cooperated with the health care system, to She get better. Wu (1973) added other characteristics. stated that people defined as sick were extremely concerned over the body and its functions; they were allowed to regress. The regression, with increased dependency, was thought to support compliance with the treatment regimen.

Kassebaum and Baumann (1972) felt that sick role expectations were largely normative in nature in today's society. These normative expectations vary in the following way:

1. People who occupied different positions in the social structure might hold different norms pertaining to the sick role or any role.

2. People differed in the intensity with which they held different norms and how these norms were evaluated. How the role expectations were perceived by a particular population group would be influenced by the perspective from which the role was viewed and saliency of the particular role expectation for the group. The role expectation would receive more or less emphasis depending on how they were valued. The sick role as it related to chronic illness was discussed in Chapter 1.

The Sick Role and Children

Campbell (1978) studied the assumption of the sick role in children hospitalized for a short period of time. He found that socialization to the sick role was a developmental process. Acquisition of sick role was related to age, sex, and socioeconomic status of parents. Older children, boys, children with mothers of higher education, and high socioeconomic status fathers were more likely to reject sick role behaviors. Campbell (1978) stated that parents did make a difference in their child's selfassessment of sick role status. Mother's educational status was a particularly strong determinant. He noted that a stoic attitude toward illness was more likely to be approved by the members of the health team.

Pratt (1973) examined child-rearing methods and their relationship to health behavior. The two child-rearing methods studied were the developmental approach, defined as the tendency to grant autonomy and control and to give reason and information, and the disciplinary approach, defined as the tendency to reward good behavior and punish misbehavior. The variables were measured by "detailed selfmade interviews" of both parents and a child. Though the study had many methodological problems and was replete with value statements, Pratt (1973) felt that she showed that the developmental approach was associated with healthy management of elimination, care of the teeth, and cleanli-The disciplinary approach was associated with ness. healthy approaches toward nutrition, smoking, and sleep habits. She concluded by stating that ability to care for one's self was associated with autonomy, and ability to conform to adult standards was associated with punative childrearing practices.

Zborowski (1952) studied the cultural component in response to pain by interviewing adults of Italian, Jewish, and "Old American" origin. He stated

Attitudes toward pain and the expected reactive patterns were acquired by the individual members of the society from the earliest childhood along with other cultural attitudes and values which were learned from parents, parent-substitutes, siblings, peer groups, etc. (pp. 16-30)

The family was an important variable in predicting a person's response to an illness cue in that they approved or disapproved specific forms of behavior. Jewish and Italian parents, particularly mothers, manifested overprotection and overconcern toward a child's health. They advised their children to avoid injury and threatening situations. Crying and complaining on the part of the child brought responses of sympathy, concern, and help on the part of the parent. In Jewish families not only pain but also deviations from the child's normal behavior were looked upon as a sign of illness. The child acquired anxieties with regard to the meaning and significance of these cues. Child-rearing practices had an effect on the illness cues to which a child would attend.

In contrast, however, Mechanic (1964) found that the mother's attitude toward illness and illness cues was a rather poor predictor of the same attitudes of their children. Mothers' attitude was a good indicator of whether or not medical aid would be sought. The best predictors of attending to pain as an illness cue was age and sex of the child. Boys were more stoical than girls and older children more stoical than younger.

Mechanic (1964) also studied male college students' reactions to hypothetical illness cues as compared to their fathers' and mothers' reactions. The findings showed that the students' reactions most closely match that of the mother, though the response varied. The mother's response pattern, as perceived by the son, showed the primacy of self-medication as a reaction to illness, and the father's response was self-medication or doing nothing, while the son's response was seeking a physician.

The Sick Role and the Child with Chronic Illness

Meadows (1968) discussed how the sick role was modified when the child was chronically ill. The sick role was divided between the parent and the ill child; the child had the symptoms, but the parent had the relationship with the health care delivery system. The parent had to carry out all the treatment but was not released from other role obligations nor given extra community supports while the child was ill. Children who had long-term illness were considered to have an extended period of dependency (Freeman, 1970; LaHood, 1970). At times the status of

youngest child was conferred on them regardless of the birth order, which also tended to extend the socially accepted period of dependency (Shere & Kastenbaum, 1966).

Swift, Steidman, and Stein (1967) demonstrated that dependency as evaluated clinically by a psychiatrist was related to poor control of juvenile onset diabetes particularly as the child grew older. This evaluation was significant at $\underline{p} < .05$.

Peterson (1972) studied the perception of adolescent relationship to parents and siblings who had experienced major illness but were well enough to be attending high school. The results could be summarized as follows:

 There was no difference in terms of familial and extrafamilial interactions between those who were ill, those who had a history of illness, and those who were well.

2. The adolescent responded to illness differently. Those adolescents who had experienced chronic illness experienced significant changes in reactions of family members, and their reactions to their family were different from those of their normal peer.

3. The adolescent who had experienced severe illness in the past evaluated illness cues differently.

4. The adolescent who had experienced severe illness feigned illness more frequently.

The following sex role differences were noted in those who had experienced chronic illness:

1. Girls provoked a greater parental concern.

2. Girls had the ability to empathize more than their male peers (Peterson, 1972).

Experience with severe illness did seem to affect the adolescent's perception about several aspects of his life. The data suggested that behavior that was unacceptable to the well adolescent was acceptable to the ill, and residual sick role behavior remained long after the acute illness was over.

The Parents of the Child with Chronic Illness

Voysey (1972) studied the strategies which parents adopted to manage interactions outside the immediate family. She felt the family was reevaluated and given a different role in the community at the diagnosis of illness or handicap. The family was stigmatized. Parents developed strategies which controlled the information moving into and out of the family. The first strategy was called "conveying the desired impression." The goal of this strategy was to produce a normal appearing child. The types of experiences which the child was exposed to were limited to those which he could appear to accomplish normally. This strategy would explain Shere and Kastenbaum's (1966) observation that parents of cerebral palsied children gave fewer toys for them to play with, spoke to them less, and were concerned that their child make a "good" first impression.

The second strategy was called "breaking through." The goal of this strategy was to define the status of the child and to negotiate how societal expectations were to be modified for him. The third strategy was called "information control." The parent decided who would be allowed to know the child's condition and who would not. Parents would behave as if the child was normal in the presence of people unknown to the family. These people would receive only selected bits of information about the child's "condition." The fourth strategy was called "obtaining information." The goal was to obtain from another person an estimation of the child's "true identity" and to seek trustworthy advice (Voysey, 1972).

The Voysey (1972) study indicated that child-rearing practices were modified with chronic illness. Parents were continually negotiating with society concerning the expectations toward these ill and disabled children. Parents attempted to modify society's assessment of the child's worth.

Data suggested that parents adapted to their children's long-term illness and disability and that this adaptation

occurred in stages. Meadows (1968) defined the following three stages: the diagnostic funnel, the diagnostic trauma, and alliance for treatment. In the diagnostic funnel, parents suspected something was going wrong and sought diagnosis. Diagnostic trauma occurred at diagnosis. The parents grieved the loss of their normal child and began to gain a cognitive appreciation for what was known about the problem. Parents often sought support from others. They also began to resolve their part in the causality of the illness and the social stigma it produces. Anger was often a part of this work of resolution. The alliance for treatment occurred when the parent turned away from the health team as a source of all support. They sought the support from an alliance with knowledgeable lay persons (Meadows, 1968). McCollum and Gibson (1970) identified similar stages of adaptation to cystic fibrosis. These stages were listed as follows: prediagnostic, confrontation, long-term adaptive, and terminal.

Mattsson (1972) had identified the characteristics of the parent who had adapted to the child's long-term illness as follows: (a) only necessary restrictions were enforced, (b) self-care on the part of the child was encouraged, (c) regular school attendance was encouraged, and (d) reasonable physical activities were promoted. He stated

that parental adaptation was related to the ability to master resentful and self-accusatory feelings over having in some way caused the disease.

The parent of the chronically ill child had the responsibility for socializing him into the culture. The chrnoically-ill child would need to marshal resources to maintain health as he reached adulthood. The adult would need to respond to illness cues in such a way that he prevented further illness and disability and would need to engage in role appropriate behavior. Society's conferring of sick role status on the child with long-term illness had both positive and negative effects. On one hand, this role relieved the child of responsibility of competing in areas which he was incapable of competing. On the other hand, society asked this person to accept his state of health as bad and himself as less worthwhile. Society supported this person as he sought treatment for his health problems, but it also asked that he be dependent in his acceptance of this treatment. The parent was the one who mediated between the society and the child.

There were two studies which implied that parents could influence the physiological adaptation of their children to juvenile onset diabetes. Swift et al. (1967) found that control of juvenile onset diabetes was related to ajustment

at home with a significance at $\underline{p} = .05$. Mothers of diabetics showed more extremes in parent behavior, e.g., protection to neglect, domination to submission. Fathers showed more extremes in domination to submission behavior. This was the only study that considered fathers and mothers separately. Khurana and White (1970) interviewed 50 children ages 10 to 15 attending camp and their parents. They found that over anxious, over indulgent, perfectionist, and apparently normal mothers had children with good control. Indifferent parents had children with poor control. No statistical manipulation of the data was attempted.

Summary

The factors which influenced a family's adaptation to chronic illness had been discussed. The parent's total environment affected how he would perceive his role and the kind of models chosen. Signs, symptoms, and treatment of disease, age at diagnosis, and chronological age affected child-rearing tasks and interactions. The parent's attitude toward illness, and society's attitude toward illness affected how the parent saw his role and who he chose for role models for child-rearing. Parents negotiated with society regarding the health status of the child. Two studies have demonstrated that child-rearing variables

affected the health status of children. The limitation in knowledge in this area was obvious. The purpose of this study would be to identify child-rearing practices of children with chronic illness as compared to their well siblings.

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

The purpose of this chapter will be to discuss the methodology of this study. It will be divided into the following seven parts: Setting, population and sample, protection of human subjects, instrument data collection, and treatment of data.

Setting

Nineteen parents agreed to participate in the study. The parents filled out the questionnaire in their own homes at a time of the parent's choosing. Most of the interviews took place in the evening. The researcher administered the questionnaire and was present the entire time that the parents had the questionnaire.

Population and Sample

The sample for this study was selected from a large, private health care facility. The records were searched to identify families who met the criteria for participating in the study. The subjects met the following criteria for the study:

 Had two children between the ages of 4 and 14, one of whom was a child with chronic illness.

2. Both parents resided in the home at the time of the study, and were available for appointment.

The parents of the child were defined as those persons who had legal responsibility for the children. Parents could be either natural or adoptive.

Parents who met the criteria for admission to the study were sent a letter from the hospital. If the parent agreed to be contacted by the researcher they mailed back a card. Follow up letters were sent to those parents not responding to the first letter. All parents who responded positively were contacted and asked to participate in the study. The entire available population was used in this study.

Protection of Human Subjects

Ethical and legal issues have been considered in the implementation of this study. Every effort was made to protect the interest of the subject.

Subjects were contacted by phone and asked to participate in the study. If the subject met the criteria for admission to the study, the consent form was read (see Appendix B). This study was a part of validity and reliability studies being carried out by the Institute for Personality and Ability Testing, but no names were sent to them. Certain demographic variables were requested by the institute (see Appendix C). If the subjects agreed to

participate in the study, an appointment was made for them to fill out the questionnaire. The subjects read and signed the consent form prior to filling out the CRPQ.

There is a potential risk to privacy in participating in the study. No names of subjects were released. No individual scores, only group data were released. The raw data will be destroyed within 2 years of the completion of the study.

Prior to the beginning of the study, it was cleared by the Human Research Review Committee of Texas Woman's University. Agency permission was also obtained. The results of the study was shared with the participating agency (see Appendix D, E, and F).

Instrument

The instrument which was used was the Child-Rearing Practices Questionnaire (CRPQ) which has been developed by the Institute for Personality and Ability Testing in Champaign, Illinois. The instrument is a self-report questionnaire.

The CRPQ gives scores for both fathers and mothers on the following factors: Factor I, use of punishment vs. reason; Factor II, promotion of independence vs. dependence; Factor III, levels of rules of behavior used; Factor IV, amount of spouse involvement; Factor V, level of rewarding 50

children; and Factor VI, preference for younger vs. older children. Factor VII, motivational distortion, is used to evaluate truth telling on the other six variables. The variables are considered to be continuous variables. High scores are to the right side, while the left side are the low scores (see Figure 3). The answer sheets were sent to the Institute for Personality and Ability Testing for scoring.

Factor	High Score Indicates:	Low Score Indicates:
I	High use of reason with children (low use of punishment)	High use of punishment with children (low use of reason)
II	Promotion of dependence in children by parent	Promotion of indepen- dence in children by parent
III	High use of rules with child-rearing	Low use of rules with child-rearing
VI	High level of spouse involvement in child- rearing	Low level of spouse involvement in child- rearing
V	High use of rewards with child-rearing	Low use of rewards with child-rearing
VI	Preference for older children	Preference for younger children
VII	High level of motiva- tional distortion	Low level of motiva- tional distortion

Figure 3. Description of CRPQ factors.

The range of scores on each factor is 0 to 100. The testretest reliability using Pearson's r in a small group at 3-month intervals between testing is listed as follows: Factor I, .843; Factor II, .691; Factor III, .547; Factor IV, .959; Factor V, .842; and Factor VI, .671 (Madsen, 1979). The following variables were used in the study: Factor I, use of punishment vs. reason; Factor II, promotion of independence vs. dependence; Factor III, levels of rules of behavior used; and Factor IV, amount of spouse involvement.

The questionnaire consists of 143 multiple-choice items (see Appendix A). The parent responded with pencil on an answer sheet. It took approximately 45 minutes to complete one questionnaire.

Previous forms of this tool have been validated for use with parents of children between the ages of 4 and 14. Previous forms have been used to predict personality factors in school age and teenage children, school achievement in children ages 6 to 8 years of age, and behavior problems in children ages 6 to 8 years of age. (Barton, Dielman, & Cattell, 1974; Barton, Dielman, & Cattell, 1977; Dielman & Cattell, 1972; Dielman, Cattell, & Rhodes, 1972).

Data Collection

The researcher went to the parent's home at the appointed time. Prior to going to the home, the well

sibling who would be participating in the study was selected with the use of a random number table. The order which the parents completed the questionnaire was selected by fliping a coin. Parents were asked to read and sign consent forms. Next, the parents were asked to fill out the forms in Appendix B. Fathers and mothers completed questionnaires in the order prescribed by the coin toss.

Treatment of Data

Descriptive data for the child-rearing variables was obtained by deriving intercorrelations in the following categories: overall scores, health status of the child, sex of parent, mothers of children with chronic illness, mothers of well sibling, fathers of children with chronic illness, fathers of siblings. An SPSS package was used. Multiple analysis of variance and covariance (MANOVA) was used to test the following hypothesis: There will be a significant difference in mothers' scores and fathers' scores for children with chronic illness and their well siblings on the following four variables:

- 1. Use of punishment vs. reason
- 2. Promotion of independence vs. dependence
- 3. Level of rules of behavior
- 4. Amount of spouse involvement (see Figure 2)

All of the following mean scores on the CRPQ are equal:

1. Mothers and fathers

2. Child with chronic illness and well siblings

3. Mother scores on children with chronic illness and mother scores on well siblings

4. Father scores on children with chronic illness and father scores on well siblings

BMD 12V computer package was used for computation.

The assumptions of MANOVA are listed as follows:

1. Random sample

2. Normal population

3. Homogenity of variance

4. Homogenity of covariance

5. Independent groups

Every attempt was made to select a random sample from a normal population. The entire available population was used to obtain sufficient sample size. The sample is assumed to be representative of the entire population.

The Box test was done to test the assumption of homogenity of variance and covariance. An <u>F</u> of 1.4043 was obtained which had a <u>p</u> value of .1715. It is reasonable to assume homogenity of variance and covariance.

The assumption for independent groups could not be met since mothers and fathers and brothers and sisters were used for the cells of the MANOVA. The scores were related. Using the MANOVA in this setting is a conservative test. The probability of rejecting the null hypothesis is less than the stated alpha level.

A univariate analysis of variance (ANOVA) was computed on the variable which obtained significance in the MANOVA to determine the source of the variance. A discriminant analysis was computed to confirm the results of the ANOVA.

CHAPTER 4

ANALYSIS OF THE DATA

The first portion of this chapter is a description of the sample in terms of the characteristics of the parents, and the characteristics of the children. The second portion of the chapter describes the findings of the study in terms of the hypothesis.

Description of Sample

The records of a large family practice were searched to identify families who met the criteria for participating in the study. One hundred and twenty families were identified. A letter was sent to these families requesting that they participate in the study (see Appendix G). A follow up letter was sent to the 71 persons not responding to the first letter (see Appendix H). Sixty-eight families responded to the letters. Fifty families agreed to participate in the study and 18 refused, making a 56.7% return on the inquiry letters and a 41.7% positive return.

Fifty families agreed to participate in the study; however, 31 families were excluded from participation. The reasons for exclusion are listed as follows: diagnosis error, error in ages of children, all children ill, ill

child not in family, the ill child was an only child, the family moved, parents were divorced, unable to find the family, or not able to schedule an appointment.

The remainder of the discussion of the sample will be divided into two parts. The first part will discuss the characteristics of the parents; the second part will discuss the characteristics of the children.

Characteristics of the Parents

The purpose of this section will be to discuss the characteristics of the parents who participated in the study. The following characteristics will be discussed: age, years married, times married, ethnic origin, and occupation status.

Nineteen families met the requirements for inclusion in the study. The mean age of the 19 mothers was 36.211 ± 4.708 <u>SD</u>. The range of ages for the fathers was 30 to 48. In eight of the families the mother was older than the father.

The mean number of years of marriage for the mothers was 15 years \pm 3.261 <u>SD</u>. The range for the years of marriage for the mothers was 10 to 23. The mean number of years of marriage for the fathers was 14.949 years \pm 4.560 <u>SD</u>. The range for the years of marriage for the fathers was 10 to 31.

The mean number of times of marriage for the mothers was $1.316 \pm .465 \text{ <u>SD</u>}$. Thirteen of the 19 mothers had been married one time. Six had been married two times. The mean number of times of marriage for the fathers was $1.263 \pm .547$ <u>SD</u>. Fifteen of the 19 fathers had been married one time. Three had been married two times. One had been married three times.

All of the parents characterized themselves as being caucasian in origin. Four of the mothers stated further ethnic origins. One mother was Mexican-American, one was Polish American, one was American Indian, and one was Chilian in origin. Three of the fathers stated further ethnic origin. One father was Mexican-American, one was Arcadian French, and one was Brazilian in origin. All of the parents were American citizens.

Twelve of the 19 mothers were employed outside the home. The occupations of the mothers are listed as follows: office manager, two; registered nurse, one; liscensed vocational nurse, one; teacher, three; supervisor of sales, one; insurance claims adjustor, one; clerk, one; secretary, one; and real estate agent, one. These 12 women made up 63.2% of the sample. Seven of the 19 mothers or 36.8% listed their occupation as housewife.

All of the 19 fathers worked outside the home. The occupations of the fathers are listed as follows: engineer,

seven; salesman, three; systems engineer, two; supervisor, two; comptroller, one; consultant, one; service manager, one; personnel director, one; and foreman, one.

Characteristics of Children

The mean number of children living in the 19 families admitted to the study was $2.789 \pm .766 \text{ SD}$. The range in the number in the families was two to five. There was a total of 53 children in these families. The mean age of all the children in the families studied was 10.821 years \pm 3.809 <u>SD</u>. The range of ages for all the children in the families is 5 to 20 years.

The mean age of the children with chronic illness and their well siblings included in the study was 9.618 years \pm 2.794 <u>SD</u>. The range of the ages of all children included was 5 to 14 years.

The mean age of the children with chronic illness was 9.632 years ± 3.012. The range of ages for the ill children was 5 to 14 years.

The mean age of the well siblings included in the study was 9.603 years ± 2.558 SD. The range of ages for the siblings included in the study was 5 to 14 years.

In order to determine if the ages of the children with chronic illness and their well siblings was equal, a <u>t</u> test for dependent groups was done testing Ho: $\mu_1 - \mu_2 = 0$.

The computed \underline{t} of .02777 was not significant at the .05 level. The null hypothesis was retained indicating that the ages of the children with chronic illness and their sibling did not differ significantly.

An equal proportion of males to females was obtained for both the children with chronic illness and their siblings. In both groups there were 12 males and seven females.

The diagnoses of the children with chronic illness are listed as follows: asthma, seizure disorder, juvenile diabetes, acute glomerulonephritis, bacterial endocarditis with heart block, and thalasemia minor. Twelve of the ill children have asthma. Three of the children have seizure disorders. One child has each of the following diagnoses: juvenile diabetes, acute glomorulonephrites, bacterial endocarditis with heart block, and thalasemia minor.

The mean number of years since diagnosis for the children with chronic illness was $4.659 \pm 2.938 \text{ SD}$. The range of the number of years since diagnosis was 6 months to 12 years. The mean number of years since diagnosis for the children with asthma was $5.333 \pm 2.981 \text{ SD}$. The range was 1 year, 6 months to 12 years. The mean number of years since diagnosis for the children with seizure disorder was $5.5 \pm 2.25 \text{ SD}$. The range was 6 months to 7 years.

Findings

The part of the chapter devoted to findings is divided into two parts. The first part will be a description of the study variables. The second part will be a discussion of the testing of the hypothesis.

Description of Study Variables

Descriptive data for the child-rearing variables in the following categories is provided in this section. Overall scores, sex of parent, health of child, father with well child, mother with well child, father with ill child, mother with ill child. SPSS computer package was used to derive the intercorrelations.

Child-rearing practices were determined by the use of the Child-Rearing Practices Questionnaire (CRPQ). The variables used in this study are listed as follows: Factor I, use of punishment vs. reason; Factor II, promotion of independence vs. dependence; Factor III, levels of rules of behavior used; Factor IV, amount of spouse involvement; and Factor VII, level of motivational distortion (see Figure 3). The range of possible scores is 0 to 100.

Overall Scores

Table 1 shows the scores in terms of mean, standard deviation, and range for all the child-rearing variables

studied. The scores which are included are tested as follows: scores of mothers of well siblings and child with chronic illness, fathers of well sibling and child with chronic illness.

Table 1

CRPQ Variable Mean, Standard Deviation, and Range for Total Data

Variable	Mean	SD	Range
Reason	43.592	6.706	26 to 58
Dependence	37.895	4.612	29 to 48
Rules	35.250	4.767	23 to 47
Spouse	44.026	8.748	21 to 56
Motivation	12.329	2.312	6 to 18

 \underline{n} = 76, all questionnaires in the study, mothers of well sibling and ill child, fathers of well sibling and ill child.

Pearson's Product Moment Correlation coefficients were computed on all the scores and a correlation matrix was derived. These correlation coefficients are presented in Table 2.

Two of the correlation coefficients were significant at the .05 level. There was a significant inverse correlation between Factor I, use of punishment vs. reason, and

Table 2

Variable	Pearson's <u>r</u>	<u>p</u>
Reason with dependence	154	.184
Reason with rules	237	.039*
Reason with spouse	.051	.661
Reason with motivation	010	.931
Dependence with rules	220	.057
Dependence with spouse	.124	.287
Dependence with motivation	.036	.759
Rules with spouse	244	.033*
Rules with motivation	.076	.514
Spouse with motivation	.077	.507

Correlation Coefficients for CRPQ Variables on all the Scores

*Significant at the .05 level

n = 76, all questionnaires in the study, mothers of well sibling and ill child, fathers of well sibling and ill child.

Factor III, levels of rules of behavior. As the use of reason increased, the number of rules of behavior decreased. There was a significant inverse correlation between Factor III, levels of rules of behavior, and Factor IV, amount of spouse involvement. As the number of rules increased, the amount of spouse involvement decreased.

There was a low mean motivational distortion score and the motivational distortion score was not significantly correlated to the other factors. This implies that there was a high degree of truth telling in the parents.

Mother Scores

Table 3 shows the scores of the mothers in terms of the means, standard deviation, and range for all the childrearing variables studied for both the sick and well child.

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Variable	Mean	SD	Range
Reason	43.368	7.280	30 to 58
Dependence	36.895	4.398	29 to 46
Rules	35.763	4.962	23 to 47
Spouse	40.868	8.597	21 to 57
Motivation	12.211	2.042	6 to 18

Table 3

CRPQ Variable Mean, Standard Deviation, and Range for Mothers

n = 38, mothers of well sibling and mothers of ill ill child.

Pearson's Product Moment correlation coefficients were computed on the scores of the mothers and a correlation matrix was derived; the correlation coefficients are presented in Table 4.

Table 4

Correlation Coefficients for CRPQ Variables for Mother's Scores

Variable	Pearson's <u>r</u>	<u>q</u>
Reason with dependence	332	.042*
Reason with rules	049	.769
Reason with spouse	155	.325
Reason with motivation	300	.067
Dependence with rules	119	.477
Dependence with spouse	058	.728
Dependence with motivation	.086	.604
Rules with spouse	.271	.100
Rules with motivation	.008	.963
Spouse with motivation	.074	.659

*Significant at the .05 level

 \underline{n} = 38, Mothers of well siblings and mothers of the well child.

One of the correlation coefficients for mothers was significant at the .05 level. There was a significant inverse correlation between Factor I, use of punishment vs. reason, and Factor II, promotion of independence vs. dependence. As the use of punishment increased, the promotion of independence decreased.

There was a low level of motivational distortion on the mother's scores; the mean was 12.211 ± 2.042 SD. This implies that there was a high degree of truth telling.

Father Scores

Table 5 shows the scores of the fathers in terms of the mean, standard deviation, and range for all the childrearing variables used.

Table 5

CRPQ	Variable	Means,	Sta	andard	Deviation,
	and	Range	for	Father	S

Variable	Mean	SD	Range
Reason	43.816	6.168	26 to 55
Dependence	38.895	4.660	30 to 48
Rules	34.737	4.572	28 to 45
Spouse	47.184	7.794	25 to 61
Motivation	12.447	2.575	8 to 18

n = 38, Fathers of well siblings and fathers of ill child.

Pearson's Product Moment correlation coefficients were computed on the scores of the fathers and a correlation matrix was derived. The correlation coefficients are presented in Table 6.

Table 6

Correlation Coefficient for CRPQ Variables for Father's Scores

Variable	Pearson's <u>r</u>	<u>p</u>
Reason with dependence	.018	.914
Reason with rules	473	.003*
Reason with spouse	.298	.069
Reason with motivation	.257	.119
Dependence with rules	288	.080
Dependence with spouse	.161	.336
Dependence with motivation	021	.902
Rules with spouse	162	.330
Rules with motivation	148	.375
Spouse with motivation	.055	.743

*Significant at the .01 level

n = 38, Fathers of well sibling and child with chronic illness.

One of the correlation coefficients for fathers was significant at the .01 level. There was a significant inverse correlation between Factor I, use of punishment vs. reason, and Factor III, levels of rules of behavior. As use of reason increased, the level of rules decreased.

There was a low mean level of motivational distortion score and the level of motivational distortion score was not significantly correlated to other factors. This implies that there was a high degree of truth telling in fathers.

Scores on Well Siblings

Table 7 shows the scores for the well siblings in terms of means, standard deviations, and range for all of the child-rearing variables studied.

Table 7

Variable	Mean	SD	Range
Reason	43.763	5.805	30 to 55
Dependence	38.211	4.509	29 to 48
Rules	35.105	5.071	23 to 45
Spouse	44.026	9.228	21 to 61
Motivation	12.500	2.227	8 to 18

CRPQ Variable Mean, Standard Deviation, and Range for Well Siblings

 $\underline{n} = 38$, Mothers for well siblings and fathers for well siblings.

Pearson's Product Moment correlation coefficients were computed and a correlation matrix for siblings was derived. The correlation coefficients are presented in Table 8. None of the correlation coefficients for well siblings were significant at the .05 level. There was a low level of motivational distortion score and the level of motivational distortion score was not significantly correlated to other

Table 8

Correlation	Coefficients	for CRPQ
Variables	for Siblings	Scores

Variables	Pearson's <u>r</u>	p
Reason with dependence	161	.334
Reason with rules	253	.126
Reason with spouse	.153	.361
Reason with motivation	.035	.837
Dependence with rules	265	.108
Dependence with spouse	.201	.226
Dependence with motivation	029	.860
Rules with spouse	314	.055
Rules with motivation	.108	.520
Spouse with motivation	.084	.618

n = 38, Mothers of well siblings and fathers of well siblings.

CRPQ factors. This implies that there was a high degree of truth telling in relation to siblings.

Scores on Children with Chronic Illness

Table 9 shows the scores for the children with chronic illness in terms of means, standard deviations, and range for all of the child-rearing variables studied.

Table 9

Variable	Mean	SD	Range
Reason	43.421	7.575	26 to 58
Dependence	37.579	4.751	31 to 46
Rules	35.395	4.506	28 to 47
Spouse	44.026	8.365	25 to 57
Motivation	12.158	2.411	6 to 18

CRPQ Variable Mean, Standard Deviation, and Range for Children with Chronic Illness

 $\underline{n} = 38$, Mothers of children with chronic illness and fathers of children with chronic illness.

Pearson's Product Moment Correlation coefficients were computed and a correlation matrix for children with chronic illness was derived. The correlation coefficients are presented in Table 10. None of the correlation coefficients for children with chronic illness were significant. The mean motivation distortion score was low and did not correlate with the other CRPQ variables. This implies that there was a high degree of truth telling in all the variables studied.

Table 10

Correlation Matrix for CRPQ Variables for Children with Chronic Illness

Variables	Pearson	s <u>r p</u>
Reason with dependenc	e154	.356
Reason with rules	231	.163
Reason with spouse	033	.844
Reason with motivatio	n 045	.788
Dependence with rules	170	.307
Dependence with spous	e .044	.794
Dependence with motiv	ation .083	.617
Rules with spouse	158	.343
Rules with motivation	.048	.771
Spouse with motivatio	n .072	.667

 $\underline{n} = 38$, Mothers of children with chronic illness and fathers of children with chronic illness

Mother Scores on Well Siblings

Table 11 shows the scores of the mothers of well siblings in terms of means, standard deviations, and range for all of the child-rearing variables studied.

Table 11

CRPQ Variable Mean, Standard Deviation, and Range for Mothers of Well Siblings

Variable	Mean	SD	Range
Reason	43.053	6.433	30 to 55
Dependence	37.263	3.984	29 to 43
Rules	36.105	5.238	23 to 45
Spouse	40.053	9.300	21 to 56
Motivation	12.368	2.061	8 to 15

n = 19, Mothers of well siblings.

Pearson's Product Moment Correlation coefficients were computed and a correlation matrix for mothers of well siblings was derived. The correlation coefficients are presented in Table 12.

None of the correlation coefficients for mothers of siblings were significant at the .05 level. The correlation score for mothers of siblings and the level of motivational distortion scores did not correlate significantly with the other CRPQ factors. This implies that there was a high degree of truth telling in mothers of siblings.

Table 12

Correlation Coefficient for CRPQ Variables for Mothers of Well Siblings

Variable	Pearson's <u>r</u>	p
Reason with dependence	386	.051
Reason with rules	048	.423
Reason with spouse	190	.219
Reason with motivation	140	.284
Dependence with rules	273	.129
Dependence with spouse	.086	.362
Dependence with motivation	040	.436
Rules with spouse	071	.059
Rules with motivation	.022	.464
Spouse with motivation	.001	.498

n = 19, mothers of well siblings.

Mother Scores of Children with Chronic Illness

Table 13 shows the scores for mothers of children with chronic illness in terms of means, standard deviations, and range for all of the child-rearing variables studied.

Table 13

	with Chroni	c Illness	
Variables	Mean	SD	Range
Reason	43.684	8.206	30 to 58
Dependence	36.526	4.857	30 to 46
Rules	35.421	4.788	23 to 47
Spouse	41.684	8.000	25 to 57
Motivation	12.053	2.068	8 to 15

CRPQ Variable Mean, Standard Deviation, and Range for Mothers of Children with Chronic Illness

n = 19, Mother of children with chronic illness.

Pearson's Product Moment Correlation coefficients were computed and a correlation matrix for mothers of children with chronic illness was derived. The correlation coefficients are presented in Table 14.

One of the correlation coefficients for mothers of children with chronic illness was significant at the .05 level. There was a significant inverse correlation between Factor I, use of punishment vs. reason, and Factor VII, level of motivational distortion. As the use of punishment increases, the level of motivational distortion increases.

There was a low level of motivational distortion score, the mean score was 12.053, and the correlation of level of motivational distortion was not significantly correlated to the other factors. This implies that there was a high degree of truth telling in mothers of children with chronic illness in all factors except Factor I.

Table 14

Correlation Coefficient for CRPQ Variables for Mothers of Children with Chronic Illness

Variable	Pearson's <u>r</u>	<u>p</u>
Reason with dependence	294	.111
Reason with rules	046	.426
Reason with spouse	140	.284
Reason with motivation	425	.035*
Dependence with rules	.004	.493
Dependence with spouse	183	.227
Dependence with motivation	.180	.231
Rules with spouse	133	.294
Rules with motivation	019	.469
Spouse with motivation	.179	.232

*Significant at the .05 level $\underline{n} = 19$, Mothers of children with chronic illness.

Father Scores of Well Sibling

Table 15 shows the scores for the fathers of well siblings in terms of means, standard deviations, and range for all of the child-rearing variables studied.

Table 15

Variable	Mean	SD	Range
Reason	44.474	5.179	35 to 55
Dependence	39.158	4.902	30 to 48
Rules	34.105	4.829	28 to 45
Spouse	48.000	7.431	32 to 61
Motivation	12.632	2.432	8 to 18

QRPQ Variable Mean, Standard Deviation, and Range for Fathers of Well Siblings

n = 19, Fathers of well siblings.

Pearson's Product Moment Correlation coefficients were computed and a correlation matrix for fathers of siblings was derived. The correlation coefficients are presented in Table 16.

One of the correlation coefficients for fathers of siblings was significant at the .05 level and one was significant at the .01 level. There was a significant

Table 16

Correlation Coefficients for CRPQ Variables for Fathers of Well Siblings

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Variables	Pearson's <u>r</u>	p
Reason with dependence	008	.488
Reason with rules	486	.017*
Reason with spouse	.576	.005**
Reason with motivation	.204	.201
Dependence with rules	200	.206
Dependence with spouse	.166	.284
Dependence with motivation	046	.426
Rules with spouse	105	.334
Rules with motivation	.216	.187
Spouse with motivation	.135	.290

*Significant at the .05 level
**Significant at the .01 level
n = 19, Fathers of well siblings.

inverse correlation between Factor I, use of punishment vs. reason, and Factor III, level of use of rules of behavior used. As the use of reason increased, the use of rules decreased. There was a significant positive correlation between Factor I, use of punishment vs. reason, and Factor IV, amount of spouse involvement. As the use of reason increased, the spouse involvement increased.

There was a low level of motivational score for fathers of siblings; the mean was 12.632, and the level of motivational score was not significantly correlated to the other CRPQ factors. This implies that there was a high degree of truth telling in fathers of siblings.

Father Scores of Children with Chronic Illness

Table 17 shows the scores for the fathers of children with chronic illness in terms of means, standard deviations, and range for all the child-rearing variables studied.

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CRPQ Variable Mean, Standard Deviation, and Range for Fathers of Children with Chronic Illness

Variable	Mean	SD	Range
Reason	43.158	7.105	26 to 54
Dependence	38.632	4.524	31 to 46
Rules	35.368	4.336	28 to 43
Spouse	46.368	8.261	25 to 54
Motivation	12.263	2.766	6 to 18

n = 19, Fathers of children with chronic illness.

Pearson's Product Moment Correlation coefficients were calculated and a correlation matrix for fathers of children with chronic illness was derived. The correlation coefficients are presented in Table 18.

Table 18

Correlation Coefficients for CRPQ Variables For Fathers of Children with Chronic Illness

Variables	Pearson's <u>r</u>	<u>p</u>
Reason with dependence	.028	.455
Reason with rules	467	.022*
Reason with spouse	.105	.334
Reason with motivation	.283	.120
Dependence with rules	384	.053
Dependence with spouse	.147	.275
Dependence with motivation	005	.492
Rules with spouse	196	.210
Rules with motivation	.107	.331
Spouse with motivation	022	.465

*Significant at the .05 level n = 19, Fathers of children with chronic illness.

One of the correlation coefficients for fathers of children with chronic illness was significant at the .05 level. There was a significant inverse correlation between Factor I, use of punishment vs. reason, and Factor III, level of use of rules of behavior used. As the use of reason increased, the use of rules decreased.

There was a low mean level of motivational distortion score for fathers of children with chronic illness and the level of motivational distortion score did not correlate significantly with the other CRPQ factors. This implies that there was a high degree of truth telling in fathers of children with chronic illness.

Test of the Hypothesis

The research hypothesis is stated as follows: There will be a significant difference in mothers' scores and fathers' scores for children with chronic illness and their well siblings on the following four variables:

- 1. Use of punishment vs. reason
- 2. Promotion of independence vs. dependence
- 3. Level of rules of behavior
- 4. Amount of spouse involvement

The global null hypothesis is stated as follows: All of the following mean scores on the CRPQ variables are equal:

1. Mothers and fathers

2. Child with chronic illness and siblings

3. Mother scores on children with chronic illness and mother scores on well siblings

4. Father scores on children with chronic illness and father scores on well siblings (Figure 2)

The F-ratios computed by BMD 12V are presented in Table 19.

Table 19

MANOVA Summary Table for CRPQ Scores	
Source	F
Parent	3.4432*
Health	.1132
Parent/Health	.3558

*Significant for F(95, 4, 69) = 2.490

The <u>F</u>-Ratio computed for the parent variable was significant at p < .05. Null hypothesis 1, that there was no difference in parent's scores, was rejected. The <u>F</u>-Ratio computed for the health status of the child was not rejected. Null hypothesis 2, that there was no difference in scores related to the health status of the child, was retained. Null hypothesis 3 and 4, that there was no difference in scores related to an interaction between sex of parent and health status of child, was retained. A univariate analysis of variance (ANOVA) was computed on parent variable. The following null hypothesis was established: There is no difference between father's and mother's score on the following variables:

- 1. Use of punishment vs. reason
- 2. Promotion of independence vs. dependence
- 3. Level of rules of behavior
- 4. Amount of spouse involvement

Table 20 presents the results of the ANOVA statistic.

Table 20

ANOVA Summary for CRPQ for Mothers and Fathers Scores

Variables	F	<u>p</u>
Reason	.0835	.773
Dependence	3.7020	.058
Rules	.8793	.351
Spouse	11.2600	.0013*

*Significant at the .01 level

The null hypothesis that there is no difference between parent scores on the use of punishment vs. reason variable was retained. The null hypothesis that there is no difference between parents' scores on the promotion of independence vs. dependence variable is retained. The <u>F</u>-Ratio did approach significance having a <u>p</u> value of .058. The null hypothesis that there is no difference between parents' scores on the level of rules of behavior was retained. The null hypothesis that there is no difference between parents' scores on the spouse involvement variable was rejected. Parents differed on their spouse involvement scores and the difference was significant at the .01 level.

The mean score for mothers was 40.868 while the mean score for fathers was 47.184. High scores mean a high level of spouse involvement while a low score means a low level of spouse involvement. Mothers see their spouse as being less involved; fathers see their spouse involved.

The discriminant analysis confirmed the results of the ANOVA. The program terminated after the first step; only Factor IV, spouse involvement, was entered.

Summary of Findings

The findings of the study are listed as follows:

 There is no relationship between the health status of the child and the child-rearing variables.

2. There is no interaction between the health of the child and the sex of the parents which affects the child-rearing practices.

3. There is a difference between fathers and mothers on Factor IV, amount of spouse involvement. Fathers feel that mothers are more involved in child-rearing than mothers feel that fathers are involved.

4. Factor I, use of punishment vs. reason, and Factor III, levels of rules of behavior, were negatively correlated in the overall scores, in the father toward sibling scores, and in father to child with chronic illness scores. Use of reason increased as use of rules decreased.

5. Factor I, use of punishment vs. reason, was positively correlated with Factor IV, amount of spouse involvement, in fathers' scores toward siblings. As the use of reason increases, the amount of spouse involvement increases.

6. Factor I, use of punishment vs. reason, was negatively correlated with Factor II, promotion of independence vs. dependence, in mothers' scores. As the use of reason increases, more independence is promoted.

7. Factor I, use of punishment vs. reason, was negatively correlated with Factor IV, motivational distortion, in mothers of children with chronic illness. As the use of reason increases, the amount of motivational distortion decreases.

8. Factor III, levels of rules of behavior, and Factor IV, level of spouse involvement, were negatively correlated

in the overall population. As the level of rules increased, the amount of spouse involvement decreased.

CHAPTER 5

SUMMARY OF THE STUDY

The purpose of this chapter is to discuss and summarize the findings of the study. The study question is stated as follows: What are the differences in child-rearing practices of fathers and mothers toward a child with chronic illness and his well sibling? The research hypothesis is stated as follows: There will be a significance between mothers' scores and fathers' scores for children with chronic illness and their well sibling on the following four variables:

1. Use of punishment vs. reason

2. Promotion of independence vs. dependence

3. Level of rules of behavior

4. Amount of spouse involvement (see Figure 2)

The remainder of this chapter is divided into four sections. The first section is a summary of the study. The second section will be a discussion of the findings. The third part will discuss conclusions and implications, and the last section will discuss recommendations for further study.

Summary

Bandura's (1977) theory of social learning was used to structure this study. Environmental determinism was the concept that was used. This concept hypothesizes that behavior is a function of the environment, B = [f (E)]. Bandura (1977) feels that people have a potential as well as a created environment.

Parents are shaped by their environment. The complex tasks of child-rearing are learned from models in the environment by a process called social learning. In unfamiliar situations, the individuals are most responsive to models. Child-rearing of children with chronic illness is an unfamiliar task for parents. Case study evidence supports the fact that parents seek advice from knowledgeable lay persons (Meadows, 1968; Voysey, 1972). If parents use different models for rearing children with chronic illness, their child-rearing practices would be different.

A sample of 19 parent pairs were selected from a population of clients of a large health care facility. The subjects met the following criteria:

1. Had two children between the ages of 4 and 11, one of whom was a child with chronic illness.

2. Both parents resided in the home at the time of the study, and were available for appointment.

Each of the parents in the pair was asked to fill out two CRPQ questionnaires. One related to the well sibling; one related to the child with chronic illness. These data were analyzed by multiple correlation, MANOVA, ANOVA, and discriminant analysis techniques. A discussion of these findings will be presented in the following section.

Discussion of the Findings

The discussion of the findings of the study will be presented in the following areas: The sample, social learning theory, the instrument, and pertinent research.

The Sample

The parents were fairly homogenous with regard to the demographic variables of age, number of years of marriage, and number of marriages. All of the fathers and 12 of the mothers worked outside the home. All of the parents considered themselves to be white in ethnic origin though some other ethnic subgroups were represented.

The ages and sexes of the children in the two groups were not statistically different. Differences in childrearing practices between the two groups of children, had they occurred, would not be because of differences in the children. All of the children attended public school and were progressing satisfactorily. There were more boys in

both the well sibling and the child with chronic illness groups.

The characteristics of the sample which may have influenced the outcome of the study will be briefly summarized. There was a high proportion of working mothers in the sample. A large proportion of the mothers were older than the fathers. There was a high proportion of boys in the study. The children with chronic illness had illness which could not be observable to most of the public.

Social Learning Theory

There was no difference in child-rearing practices of parents between a child with chronic illness and his well sibling. There continued to be no difference when sex of the parent interacted with health status of the child. These results raise many questions. Do the parents in this study not see their children as ill? Do they use the same models for their child with chronic illness as their well child?

Parents may be functioning in a perceived environment which is familiar, not unfamiliar. The need for special role models could be a function of a crisis in the health of the child or the observability of the disability.

Gliedman (1979) has compared the experience of the chronically handicapped person to the problems of other

minorities. He likens their integration into society to the phenomenon of "passing." Passing occurred in minority groups when light-skinned blacks attempted to pass as whites or Jews attempted to pass as gentiles. He identified three groups of disabled people. The first group are those who can rarely pass as able-bodied. This group includes those individuals with visable problems such as blindness, deafness, physical disability, and cosmetic disfigurement. These persons have symptoms which are considered by many to be unpleasant and obtrusive.

The second group can usually come off as able-bodied, but Gliedman (1979) feels that they pay a high psychological price for their concealment. This group included the mildly retarded, the epiletic people with reading disabilities, cancer, heart disease, and diabetes. He does identify a third group as those who are so incapacitated that they could not lead normal lives even if societal prejudices melted away. All of the children in this study had diseases which could be hidden. Children who can pass for able-bodied may be seen as such by their parents. The perceived environment of the parents may be familiar. There would be no need for a unique model.

Mattsson (1972) identified the characteristics of parents who had adapted to their child's long-term illness. These characteristics are listed as follows:

1. On necessary restrictions are enforced.

2. Self-care on the part of the child is encouraged.

3. Regular school attendance is encouraged.

4. Reasonable physical activities are promoted. The parents in this study seem to have adapted. None of the children seem unduly restricted. Many of the children were away at evening activities while the parents filled out the questionnaire. Self-care was not evaluated. All of the children attended regular public schools. Many of the children were reported to be active in sports. The parents may have adapted. Having overcome their feelings of guilt, the behavior of a role model would have no functional value for them. There are relatively few unknowns in the situation and no need for modeling another person's behavior.

Another hypothesis would be that parents do choose different models but are guided in their choice by their own values. Even though the models might be different individuals, the behavior being modeled is similar. The parents' behavior might not differ significantly. Much more information is needed about the use of models by parents for child-rearing.

Two of the significant intercorrelations may imply that there are differences in child-rearing practices of a small

subgroup of this sample. Factor I, use of punishment vs. reason, was inversely correlated with Factor VII, motivational distortion, in mothers of children with chronic illness. As the use of reason increases, the amount of motivational distortion decreases. Mothers may have strong or ambivalent feelings about punishing children with chronic illness. One should note at this point the positive correlation between Factor I, use of punishment, and Factor IV, low spouse involvement, in fathers of siblings.

In families where punishment is used there may be a lack of mother involvement where the sibling is involved. When the wife is involved in punishment toward the child with chronic illness, she feels uncomfortable about it. This situation could make mothers avoid punishing children with chronic illness. This could produce the out-of-control children which many practitioners describe. When the father does the punishing of the sibling, but not the child with chronic illness, the discipline in the family may not be equal among the children. Parents who use punishment may use different role models. An alternate hypothesis would be that without an acceptable role model, mothers might feel uncomfortable about punishing their child with chronic illness. Fathers who punish well siblings see their wives as less involved in the rearing of that child.

Is punishment an area of conflict? Who is used as the model for punishing behavior?

The Instrument

The CRPQ has not been used in a health care population prior to this study. There is no norming data at this time. The CRPQ has not been used within the same family for two different children. These facts cause several problems in interpretation of the data.

There are three conflicting hypotheses none of which can be ruled out. There could be differences in childrearing practices and this instrument is not powerful enough to pick it up. The results could be real.

Results found in families without a child with chronic illness, and the results from these families are similar. The results could be real, but families with a child with chronic illness are different from families without such a child.

The difference in parents' scores may be the result of the general characteristics of this instrument. Factor IV, the amount of spouse involvement, was the variable that accounted for the significant difference in parents' scores. The mean score for fathers was 47.184; the mean score for mothers was 40.868. Fathers feel that mothers are more involved in child-rearing than mothers feel that fathers

are. Masden (1980) stated that these results are probably characteristic of the CRPQ.

The major related findings are associated with the significant correlation of factors from the CRPQ. Factor I, use of punishment vs. reason, and Factor III, levels of rules of behavior, were inversely correlated in the overall scores, in father scores, father toward child with chronic illness, and in father toward sibling. As use of reason increased, use of rules decreased. Masden (1980) feels that one of the characteristics of fathers' child-rearing practices is that they do not express rules, "rules are understood not stated." Where there are many rules, there must be punishment to inforce them.

Factor I, use of punishment vs. reason, was positively correlated with Factor IV, amount of involvement in fathers' scores toward siblings. As the use of reason increased, the amount of spouse involvement increased. Fathers may feel that they have to use punishment more to stay in control if the mothers are not as involved in child-rearing. The reason the mother is not involved with child-rearing of siblings is that she is more involved with the child with chronic illness. It probably takes cooperation between parents to use reason as a consistent approach to limit setting. It is interesting to note that this correlation is significant only in siblings.

Factor I, use of punishment vs. reason, was inversely correlated with Factor II, promotion of independence vs. dependence in mothers' scores. As the use of reason increases, more independence is promoted. It is logical that these two factors occur together. Mothers may use reason so that the children can be independent and be able to monitor their own behavior. Punishment takes having an agent of punishment around. It may occur in mothers only because mothers still have the primary responsibility for child-rearing in many families.

Factor I, use of punishment vs. reason, was inversely correlated with Factor VII, motivational distortion, in mothers of children with chronic illness. As the use of reason increases, the amount of motivational distortion decreases. Mothers may have strong or ambivalent feelings about punishing children with chronic illness. This intercorrelation is more likely to be the result of having a child with chronic illness.

Factor III, level of rules of behavior, and Factor IV, level of spouse involvement, were negatively correlated in the overall population. As the level of rules increased, the amount of spouse involvement decreased. This is difficult to interpret because the spouse involvement scores between fathers and mothers are combined. This correlation is probably not meaningful.

Comparison with Other Studies

There was no difference in the scores on the childrearing practices associated with the health of the child. There were no interaction effects when sex of the parent was combined with health of the child. This result does not confirm the results of the one other study which looked at child-rearing practices as related to chronic illness. Parents either have effective parenting models or can use the same model for parenting their child with chronic illness as for parenting the sibling.

Shere and Kastenbaum (1966) found that mothers played less with their cerebral palsied child. They also presented less toys and talked less to them than they did to their siblings. There could be several reasons for this difference. Shere and Kastenbaum (1966) studied younger children than this study. Child-rearing practices and attitudes may be developmental and change over time, and different childrearing variables were studied, e.g., talking to, and playing with. The Shere and Kastenbaum (1966) study used participant observation as the measurement tool. Participant observation may give more accurate information about behavior, but there is the possibility of observer bias with this method. The researcher is limited to those childrearing practices which he can see. Parental attitudes and

parental perceptions are excluded from consideration. The cerebral palsied children in the Shere and Kastenbaum (1966) study had observable health problems. Society could see what was wrong with them and would bring different pressures to bear on the family.

Kassebaum and Baumann (1972) felt that sick role behaviors were normative in nature and Campbell (1973) felt that mothers who were in the upper socioeconomic group were more stoic in their attitude toward illness. All of the families in this study lived in affluent areas of the city and were being served by private physicians. These facts imply that the families in the present study were in upper socioeconomic groups. These parents might have more stoic attitudes toward their child's illness.

This study did not confirm Swift et al. (1967) study that there were more extremes of parenting behavior where there was a child with chronic illness. Note that this study was done on children with juvenile diabetes in a medical center setting. School age children predominated. The mean scores on the CRPQ factors clustered around 35 which is just below the midpoint of the scale. The Swift et al. (1967) study was done in a medical center using different child-rearing variables. These differences may account for the failure to confirm the results.

Conclusions and Implications

The purpose of this portion of the chapter is to discuss the conclusions and implications of the study. The first part will discuss the conclusions, while the second part will discuss the implications.

This portion of this dissertation is devoted to a discussion of the conclusions. The first part will be conclusions related to the health status. The second part will be related to the sex of the parent.

The conclusions related to the health status of the child are listed as follows:

1. Parents may not use different child-rearing models for their behavior toward children with chronic illness.

 Parents who use punishment are a subgroup who may use different models for rearing children with chronic illness and well siblings.

There may be a subgroup of children with chronic illness who have parents who do not use different childrearing practices with their child with chronic illness. These parents may not perceive different cues from society, or society may give the same support to these families that they do to other families in the community. This subgroup would have the following characteristics: 1. Be in middle or upper socioeconomic groups.

2. A child whose symptoms are relatively unobservable.

3. A child with chronic illness who is school aged.

4. An illness developed later.

5. Being treated outside a medical center. All families with chronic illness and handicapping conditions should not be thought of as the same. Gliedman's (1979) concept of "passing" and Mattsson's (1972) concept of adaptation of parents may be two concepts which can be developed to identify families who are not affected or minimally affected by society's attitude toward illness.

There seems to be a subgroup of parents who use punishment who may need support in child-rearing. Mothers of children with chronic illness may distort the truth about their use of punishment. Fathers who use punishment with siblings see their wives as not involved in child-rearing. Families who use punishment may need guidance in this area of child-rearing.

There are conclusions related to the sex of the parent variable. The following results may be the norm for the CRPQ:

1. The significant difference in the spouse involvement scores.

2. The significant inverse correlation between Factor I, use of punishment vs. reason, and Factor III, levels of rules of behavior in all of the correlations which included fathers.

3. The significant inverse correlation between Factor I, use of punishment vs. reason, and Factor II, promotion of independence vs. dependence in the 38 questionnaires filled out by mothers.

Recommendations for Further Study

The purpose of this portion of the chapter is to identify a few areas of possible study. Study questions will be identified in the following areas: Social learning theory, the CRPQ, child-rearing practices, and children with chronic illness.

Social Learning Theory

Social learning theory can be used to structure other studies of child-rearing practices. The following questions could guide such study:

 Who do parents model? Are the models related?
 How many models do the parents require for learning childrearing behavior?

2. How are models provided by society? Is the process different if the mother works, or there is a child with a handicap or disability?

3. How much chronic illness or handicap is needed for parents to require different models?

4. Are there illness related situations, e.g., diagnosis of chronic illness, which require a different model for child-rearing?

CRPQ

The CRPQ requires further exploration in two major areas. First, there is an urgent need for the norming data. Until these data are available, comparison of studies will be difficult to evaluate. The next area of inquiry should be in theory development. There is urgent need for theory to guide research regarding how childrearing variables change with the development of the child, parents, and the family over time. This work will seek to answer the following questions.

1. What child-rearing practices are stable and which change over time?

2. What environmental factors change child-rearing variables (e.g., ethnic identity)?

3. What characteristics in the child effect childrearing variables?

4. What can these child-rearing variables predict about a child's future?

Child-rearing Practices

Factor I, promotion of independence vs. dependence approached significance, $\underline{p} = .058$, in the sex of parent ANOVA. The mean for mothers was 36.859; the mean for fathers was 38.895. These data seem to suggest that fathers promote dependence while mothers promote independence. Since this result is the reverse of the usual stereotype, these results need to be repeated with a larger sample. Characteristics of this sample which could have influenced the results are the high proportion of working mothers and the high proportion of male children. Neither of these variables were controlled.

Children with Chronic Illness

This study has dmonstrated that the CRPQ can be used with children in health care settings. Studies to determine if the CRPQ variables can predict such health variables as compliance with treatment regimen, level of stress, and adaptation to illness. Should this instrument prove that it can predict these phenomena, the health care professional would have information to make decisions about attempting to change child-rearing practices.

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Summary

The CRPQ was not able to distinguish different childrearing practices toward children with chronic illness and their well siblings. Mothers and fathers may not use different role models for children with chronic illness. When punishment is used by families, fathers feel that mothers are not as involved in child-rearing toward well siblings and mothers distort answers about punishing the child with chronic illness. Further study, using social learning theory as a theoretical model, is needed to determine the use of models by parents of children with chronic illness.

APPENDIX A

CRPQ

What to Do: Inside this booklet are some questions to see how you feel about certain situations and problems involved in raising children. There are no "right" or "wrong" answers because people have their own views about the way children should be raised. All you have to do is answer what is true for you.

First, read the EXAMPLE question below and decide which answer best describes your opinion or experience.

EXAMPLE: It is very important for children to enter into group

activities such as scouting or team sports.

A) strongly agree B) agree C) disagree D) strongly disagree E) ?

If you "strongly agree" with the statement in this example, you would darken the "A" block on your answer sheet, like this: BCDE

Remember to fill in the box completely.

If you did not have an opinion at all on the statement in the example, or felt that you could not answer for some other reason, you should use the question mark "?". Thus, if you did not have an opinion on the example you would darken the "E" block on your answer sheet, like this:

A B C D

Ask now if something is not clear.

The examiner has given you a separate answer sheet and will ask you to fill in some additional information. When you are told to begin, start with number 1 and answer all of the questions. Keep these four things in mind:

- 1. Give only answers that are true for you. It is best to say what you really think.
- 2. Don't spend too much time thinking over each question. Give the first, natural answer as it comes to you. Of course, the questions are too short to give you all the information you might like, but give the best answer you can under the circumstances.
- 3. Answer every question one way or the other. Don't skip any.
- 4. You should mark an <u>A</u>, <u>B</u>, <u>C</u>, or <u>D</u> answer most of the time. Mark the last answer only when you feel you have to, because none of the others seems to be right for you.

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157 Berger Alley Lolumbus, Ohio 43206 June 15, 1980

Sear SR. Masden,

This is a note to request that you offer me to include the table page of the CRPQ in My dissortation. I will include as finished copy of the dissortation in my final correspondence with you.

Sincerely Liken H Kinp

June 18, 1980

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APPENDIX B

CHILD-REARING PRACTICES OF PARENTS OF CHILDREN WITH CHRONIC ILLNESS

Investigator: Ellen H. King, Graduate Student Client: Date: Information for Parents of a Child with a Chronic Illness to Consent to Fill Out the Child-Rearing Practices Questionnaire

We are interested in parents' ideas about how to raise children and if parents' ideas are different if the child has a recurring illness.

The Child-Rearing Practices Questionnaire has been developed to find out about how parents feel about certain situations and problems involved in raising children. Will you please fill out this questionnaire two times? In one questionnaire you will relate your feelings about raising a well child; in the other questionnaire you will relate your feelings about raising a child who has a chronic illness. Each questionnaire will take about forty-five minutes to fill out. Because this is a project, it is important that you understand the items listed below: 1) You are free to refuse to answer any questions or withdraw from participation at any Your decision about participation in this study will in time. no way effect the care you receive from your pediatrician. 2) The questionnaire will be used in a larger study which will be carried out in Champaign, Illinois by the Institute for Personality and Ability Testing. 3) I will keep your answer sheet in a safe place and will release them to no one other

than the Institute for Personality and Ability Testing. All questionnaires and information about you will be sent by mail. 4) I will release no individual information.

No medical service or compensation is provided to subjects by the University as a result of injury from participation in research.

Please ask questions.

CONSENT:

Having read the above information and received answers to all of my questions, I agree to fill out the Child-Rearing Practices Questionnaire for my well child and my ill child.

Parent's	Signature:
Parent's	Signature:
Date:	

Witness:_____

Date:

APPENDIX C

CRPQ Supplemental Information Sheet

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Please Print

Child

NOTE: The following information about you and your child(ren) is requested so we can insure that all people in the community are adequately represented. All information will be treated as confidential.

Your Name
Your Age
Your Sex (check only one): MALE FEMALE
Your present occupation
Your Racial Origin or Ethnic group
Your Test Identification Number
Your present marital status (check only one):
NEVER MARRIED MARRIED
SEPARATED OR DIVORCED WIDOW/WIDOWER
Total number of years married:* *NOTE: Use the <u>sum of years</u> if more than 1 marriage.
Total number of times married:
Number of children in the family:**
**NOTE: This may include step-children and/or foster children.
The following information is requested on all children in the family:
First Name of Age of Sex (M or F)

of Child

Child

Personal Information Form

Code Number_____

Child with Chronic Illness:

Sex	
	And the second se

Illness

Number of years of illness

Sibling:

Age_____ Sex_____

APPENDIX D

TEXAS WOMAN'S UNIVERSITY Human Research Committee

Name of In	nvestigator: Ellen H.	King Cen	ter: Denton
Address:	731 Londonderry Lane #218	Date:	June 18, 1979
	Denton, Texas 76201		

Dear Ms. King

Your study entitled <u>Child Rearing Practices of Children with Chronic Illness</u> has been reviewed by a committee of the Human Research Review Committee and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education and Welfare regulations require that written consents must be obtained from all human subjects in your studies. These forms must be kept on file by you.

Furthermore, should your project change, another review by the Committee is required, according to DHEW regulations.

PLEASE ADD TO INFORMED CONSENT FORM:

NO MEDICAL SERVICE OR COMPENSATION IS PROVIDED TO SUBJECTS BY THE UNIVERSITY AS A RESULT OF INJURY FROM PARTICIPATION IN RESEARCH. Sincerely, Student Assistant to Human Research Committee

alma Cruz

Chairman, Human Research Review Committee at _______.

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APPENDIX E

APPLICATION TO HUMAN RESEARCH COMMITTEE

Subject: Research and Investigation Involving Humans Statement by Program Director and Approved by Department Chairman

This abbreviated form is designed for describing proposed programs in which the investigators consider there will be justifiable minimal risk to human participants. If any member of the Human Research Review Committee should require additional information, the investigator will be so notified.

Five copies of this Statement and a specimen Statement of Informed consent should be submitted at least two weeks before the planned starting date to the chairman or vice chairmen on the appropriate campus.

Title of Study:	Child Rearing Practices of Children with
	Chronic Illness
Program Director((s): Dr. Barbara Carper
Graduate Student:	Ellen H. King
Estimated beginni	ng date of study: <u>July 1, 1979</u>
Estimated duratio	on: <u>3 months</u>
	proval letter is to be sent:
Ellen H. King	
731 Londonder	
Denton, Texas	76201

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1. Brief description of the study (use additional pages or attachments, if desired, and include the approximate number and ages of participants, and where they will be obtained).

The purpose of this study will be to describe the pattern of child-rearing of chronically-ill children. A pediatrician's office will be used to obtain a sample of twenty (20) chronically-ill children who have siblings. All children will be between the ages of 4 and 13 and have both parents living in the home.

The Child-Rearing Practices Questionnaire (CRPQ) developed by the Institute for Personality and Ability Testing will be the measurement tool used. The tool is one hundred sixty-one (161) likert type questionnaire which is filled out by the parents.

Both parents will be contacted and asked if they will agree to participate in the study. When informed consent is obtained, then both parents will be admitted to the study. Each parent will be asked to fill out two questionnaires. One questionnaire will apply to their ill child and one questionnaire will apply to their well child. The order of which questionnaire to fill out first will be (CONTINUED)

2. What are the potential risks to the human subjects involved in this research or investigation? "Risk" includes the possibility of public embarrassment and improper release of data. Even seemingly nonsignificant risks should be stated and the protective procedures described in 3. below.

The risks to the parents and child will be listed as follows:

- The portential for embarrassment should the data of an individual be accidently released.
- 2. Inconvenience of the time necessary to fill out the questionnaire.

3. Outline the steps to be taken to protect the rights and welfare of the individuals involved.

The Institute for Personality and Ability Testing is in the process of standardizing CRPQ. This researcher is participating in their validity studies. They wish the name and demographic information about the subjects (See Appendix C). To protect the rights of the parents who agree to participate in the study, these individual data will be released only to the Institute for Personality and Ability Testing for scoring and tabulation. Only group data will be released to other persons. The parents will be informed that the Institute for Personality and Ability Testing will receive the demographic data to be used in their studies.

(CONTINUED ON ATTACHED PAGE)

4. Outline the method for obtaining informed consent from the subjects or from the person legally responsible for the subjects. Attach documents, i.e., a specimen informed consent form. These may be properly executed through completion of either (a) the written description form, or (b) the oral description form. Specimen copies are available from departmental chairmen. Other forms which provide the same information may be acceptable. A written description of what is orally told to the subject must accompany the oral form.

(SEE ATTACHED PAGE)

1. Continued---

chosen by the use of the random number table. The process of filling each questionnaire will take approximately forty-five minutes making the time spent by parents approximately ninety (90) minutes.

3. Continued--

The name of the parent and the name of the child will be excluded from the Supplemental Information Sheet. The data will be identified by number only. The names will be destroyed as soon as the answer sheets have been received.

The time spent in filling out the questionnaire could be inconvenient. The researcher will make an appointment with the parents at their convenience. Should an appointment be inconvenient, the parents will be asked to respond to the questionnaire by mail. This will prevent severe disruption of family routine.

4. The parents will be contacted by phone and asked to participate in the study. The consent form will be read over the telephone. The parents will be asked to read and sign the consent form before they fill out the application. Any question concerning participation will be answered over the telephone and again prior to their signing the consent form (See Attached Sheets for Consent Forms).

5. If the proposed study includes the administration of personality tests, inventories, or questionnaires, indicate how the subjects are given the opportunity to express their willingness to participate. If the subjects are less than the age of legal consent, or mentally incapacitated, indicate how consent of parents, guardians, or other qualified representatives will be obtained.

The parents will be given an opportunity to express their willingness to participate in the study on two occasions. The first time will be when telephone contact is made, the second time will be when they fill out the questionnaire.

Signature of Approval	5H234	A. CARP ram Director	<u>92</u> 1)ate _	11 May 1979
Signature of Approval	Ellen H Grad	Universident	I	Date	Day 15, 1979
Signature of Approval	Dean, Depa	tment Head,	Director	Date _	5-15-19
Date receive	d by committ	ee chairman:			

APPENDIX F

TEXAS UOMAN'S UNIVERSITY COLLEGE OF NURSING DENTON, TEXAS 76204

DALLAS CENTER 1810 INVOCO ROAD DALLAS, TEXAS 75235 HOUSTON CENTER

1130 M. D. ANDERSON BLVD. HOUSTON, TEXAS 77025

AGENCY PERMISSION FOR CONDUCTING STUDY*

DACTORS CLINIC THE

GRANTS TO ELLEN H. KING

a student enrolled in a program of nursing leading to a theter's Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem: Child Rearing Practices of LHILDREN With CHRONIC Illness

The conditions nutually agreed upon are as follows:

- 1. The agency (may) ((may not) be identified in the final report.
- 2. The names of consultative or administrative personnel in the agency (may) ((may not)) be identified in the final report.
- 3. The agency (wants) (does not want) a conference with the student when the report is completed.
- 4. The agency is (uilling) (unvilling) to allow the completed report to be circulated through interlibrary loan.

5. Other Date: Signature of Agency Personnel Signature of Faculty Advisor Signature of Student

* Fill out and sign three copies to be distributed as follows: Original-Student; First copy - agency; Second copy - TMU College of Nursing.

GP:GEN T3-07026074 cd 120

APPENDIX G

Dear Mr. and Mrs.

Ellen King, a graduate student at Texas Woman's University, is interested in parents' ideas about how to raise children and if parents' ideas are different if the child has a recurring illness. We would like permission to give your name to Ms. King so that she may talk with you.

Ms. King is completing work on her doctoral degree in nursing. Would you please complete the enclosed card and return it to the Doctors' Clinic.

Sincerely

APPENDIX H

Dear Mr. and Mrs.

Recently, you received a letter from us asking you about your willingness to participate in a study being conducted by Ellen King, a Graduate student at Texas Womens University. Ms. King is completing work on her doctoral degree in nursing.

Your busy schedule probably prevented you from returning the card sent to you at that time. Would you please consider participating in the study. Complete the enclosed card and return it to Doctors' Clinic.

Sincedely,

APPENDIX I

```
Key:
     Parent
     0 = Father
     1 = Mother
     Health
     0 = Sibling
     1 = Child with Chronic Illness
     Race
     0 = white
     l = latin
     Age
     M = age of mother
    F = age of father
    S = age of child with chronic illness
    Sb = age of sibling
    Marriage
   YM = years of marriage for mother
    YF = years of marriage for father
   TM = number of marriages mother
   TF = number of marriages father
     Sex
    S = sex of child with chronic illness
   Sb = sex of sibling
    IY = years since diagnosis
```

	Parents					Children							
Family	P	lge	e Marri		iage		No. of Children	Ag	e	S	Sex IY		Illness
4 otto 20 otto 10 otto 20 otto	М	F	YМ	YF	ТМ	TF		S	Sb	S	Sb		
3	35	37	15	15	1	1	3	8	8	F	м	6	Asthma
35	31	35	15	15	1	1	2	13	9	F	F	1	Acute Glomerolo- nephritis
36	32	30	11	11	1	1	2	8	6	F	F	.5	Seizure
37	38	37	18	13	3	1	3	11	10	F	F	7	Seizure
38	34	35	13	13	1	1	3	8	8	М	F	2	Asthma
41	36	46	14	16	1	2	3	8	55	М	F	8	Asthma
50	33	33	11	11	1	1	2	5	9	М	М	2	Asthma
66	36	35	13	13	1	1	2	11	7	М	М	. 2	Asthma
71	40	38	15	15	1	1	3	14	11	М	М	5	Juvenile Diabetes
73	52	48	23	31	2	2	3	14	12	М	F	12	Asthma
85	32	36	17	14	2	1	3	5	14	F	М	1.5	Asthma
86	34	37	16	16	1	1	2	12	10	М	М	6.5	Asthma
87	43	47	19	19	1	1	5	11	1.0	F	F	4	Seizure
91	38	41	20	20	2	3	4	14	13	М	М	7	Asthma
92	36	38	14	14	1	1	2	9	13	М	М	1	Carditis
96	35	34	10	10	1	1	3	7	13	\mathbf{F}	М	6.5	Asthma
102	36	33	15	12	2	1	2	12	6	М	М	6	Asthma
103	35	34	11	11	1	1	3	5	10	М	М	4.5	Asthma
114	32	36	15	15	2	2	3	7	10	М	М	6	Thalasemia

		CRPQ	SCORES				
Family #	I	II	III	IV	VI	Parent	Health
114	47	30	31	32	14	0	0
114	41	35	33	25	13	0	1
114	42	42	34	33	11	1	0
114	41	41	32	32	11 .	1	1
103	47	37	39	50	13	0	0
103	43	41	37	51	14	0	1
103	37	41	38	46	12	1	0
103	33	42	37	45	12	1	1
102	46	36	33	55	11	0	0
102	46	31	35	53	12	0	1
102	38	36	34	48	10	1	0
102	50	34	37	46	9	1	1
96	42	38	42	47	14	0	0
96	39	34	38	47	13	0	1
96	46	35	43	30	13	1	0
96	50	31	40	40	12	1	1
92	39	44	32	48	11	0	0
92	36	39	39	53	6	0	1
92	43	29	37	42	12	1	0
92	38	31	35	43	12	1	1
91	40	33	35	45	ູ 15	0	0
91	40	37	35	41	11	0	1
91	43	37	42	33	12	1	0
91	34	35	37	37	14	1	1
87	41	43	35	38	10	0	0
87	39	43	32	46	10	0	1

		CR	CONT.	J				
Family #	I	II	III	IV	VI	Parent	·	
87	50	34	45	51	13	1	0	
87	54	32	47	48	13	1	1	
86	48	42	29	53	18	0	0	
86	51	42	30	54	18	0	1	
86	55	35	23	49	14	1	0	
86	58	35	23	48	13	1	1	
85	44	36	34	49	13	0	0	
85	52	41	28	51	12	0	1	
85	45	39	39	21	13	1	0	
85	46	46	41	25	13	1	1	
73	55	37	30	55	14	0	0	
73	54	36	33	54	14	0	1	
73	53	42	32	43	8	1	0	
73	52	41	33	41	9	1	1	
71	47	39	28	52	11	0	0	
71	44	41	29	52	11	. 0	1	
71	45	39	32	47	14	1	0	
71	48	38	34	46	14	1	1	
66	47	40	35	44	12	0	0	
66	. 44	37	38	43	12	0	1	
66	42	35	41	23 🗸	11	1	0	
66	45	33	39	34	9	1	1	
50	47	39	33	51	13	0	0	
50	46	40	36	51	13	0	1	
50	44	33	35	27	15	1	0	
50	46	30	32	31	14	1	1	

CRPQ SCORES

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		CRI	2Q SCOR				
Family #	I	II	III	IV	VI	Parent	Health
41	54	48	30	61	13	0	0
41	50	42	38	49	13	0	1
41	42	42	31	35	12	1	0
41	46	40	34	35	12	1	1
38	35	45	31	32	10	0	0
38	38	46	34	35	10	0	1
38	38	42	35	44	14	1	0
38	30	42	35	44	14	1	1
37	45	41	29	51	8	0	0
37	45	41	31	50	8	0	1
37	37	37	32	56	14	1	0
37	32	33	32	57	14	1	1
36	40	47	42	48	17	0	0
36	34	45	41	46	17	0	1
36	42	34	35	42	8	1	0
36	49	31	33	39	8	1	1
35	44	37	35	53	11	0	0
35	52	32	41	30	14	0	1
35	51	33	42	32	14	1	0
35	45	37	36	52	11	1	1
3	31	32	45	48	12	0	0
3	26	31	43	50	12	0	1
3	33	43	36	48	15	1	0
3	33	42	36	49	15	1	1

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