FAMILY STRUCTURE CHANGE ASSOCIATED WITH CHRONIC RESPIRATORY DISEASE IN CHILDREN: THE MOTHER'S VIEW

by

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ABSTRACT

This study explored the mother's view of selected changes in her family activities and relationships after a preschool child had been diagnosed with a chronic respiratory disease. Concepts of family response to stress provided the framework. An interview schedule was developed with the following content areas: general information, the treatment program, mother's daily activities, mother-sick child relationship, mother-sibling relationship, and mother-father relationship. The convenience sample consisted of nineteen mothers of preschoolers who had been seen at a university medical center's pediatric pulmonary and allergy clinics and diagnosed with a chronic respiratory disease. Asthma was confirmed or suspected in nearly all cases. The mother's prominent role emerged as guardian of the child's health. Almost all reported changes in her family activities and relationships stemmed from her constant vigilance over the child's health. Patterns of protection and dependency were found. It is recommended that a modified interview schedule be used to explore the mother's view of family structure change in other settings, especially in other kinds of families. An expanded schedule could explore other member's views of change related to illness and health care, and lead to a comprehensive family assessment tool.
Patterson, Denning, and Kutscher (1973:v) have described optimal health care for the child with chronic respiratory disease in the statement below.

Any model for an approach to the treatment of chronic and potentially lethal disease must encompass not only the basic therapeutic program but also the psychosocial complex surrounding the patient and those who render care to him. However, analysis and treatment of psychosocial elements is elusive. Often the nature of the delivery system itself obstructs the efforts of health care workers to make a thoughtful assessment of problems. The medical and nursing staff usually sees the child and his family episodically and in an artificial setting. Frequently the child and primary caretaker are the only family members known to staff. As a result of these limitations, health care workers are hampered in their efforts to be especially sensitive to the entire family situation.

The family is the world of the preschool child, and his health is strongly influenced by factors in the home. Conversely, the child's illness may have resulted in stresses to the family. These problems may not be readily apparent during a brief clinic visit, yet be of great
significance. Continuous attention needs to be directed toward the effects of the disease on parts of the family constellation.

**Purpose**

Chronic illness can produce a variety of effects on each family member. The magnitude of change resulting from illness and the way the family reorganizes to meet these challenges can differ drastically. Factors influencing family reactions to chronic illness include the kinds of change produced and the perception of the stress imposed by these changes by each family member.

**Statement of the Problem**

This study explores the mother's views of selected changes in her family activities and relationships after a preschool child has been diagnosed with a chronic respiratory disease. Both the nature of these changes and the amount of hardship associated with these changes will be investigated.

**Definition of Terms**

The following terms are used:

1. Mother's views—the situation as reported by the mother.
2. Family activities and relationships—*Family activities* are those actions and tasks which have been
assumed by the mother as a vital member of the nuclear family. **Family relationships** are those sets of dyad interactions between nuclear family members with psychological, sociological, and role behavior components. For the purposes of this study, the content of family activities and relationships will be limited to: (a) the treatment program, (b) mother's daily activities, (c) mother-sick child relationship, (d) mother-sibling relationship, (e) mother-father relationship.

3. **Nature of change**—a description of the change.

4. **Amount of hardship associated with the change**—the degree to which problems and difficulties are viewed by the mother in dealing with the change.

**Assumptions**

This study is based upon the following assumptions:

1. Illness can act as a stressor event.
2. The mother is a vital family member.
3. Illness can produce change for family members.
4. The mother is able and willing to describe changes in her family activities and relationships.
Limitations

This study is restricted by the following factors:

1. The data were dependent on the mother's reactions during one interview.
2. A convenience sample of families was used.
3. Only selected aspects of the mother's family activities and relationships were explored.
4. Mothers could have distorted reports with inaccurate information.

Significance of the Problem

Chronic illness in children is impressive by numbers alone. Travis (1976:5-7) cited a number of surveys; one found 23% of children under 17 years had at least one chronic condition, and another estimated that 1.4 million children in this country are restricted in activity and over 2 million children are handicapped and need ongoing care. Mattsson (1972:801) reported that serious illness alone affects 7-10% of all children. It is difficult to obtain statistics on chronic respiratory disease as a whole. However, asthma is thought to affect about 2% of the pediatric population (Mattsson, 1972:802). The incidence of cystic fibrosis is about 1 per 1500 white births. When one considers that chronic respiratory disease has implications for all family members as well as the sick child, the enormity of the problem is realized.
In some cases, chronic illness in the child has imposed hardship on other family members, confounding impact. Untoward results can range from acting-out behavior of the siblings to peptic ulcer in a father. Adequate family functioning may be sacrificed.

The effect of the disease on the family is especially important because the family has the responsibility of the day-to-day treatment. The caretaker evaluates the child's condition and maintains contact with the medical and nursing staff. Family disruptions could adversely affect home care and evaluation. In addition, the family provides major emotional gratification and socialization for children. Family dysfunction could result in intra- and inter-personal deficiencies as the child grows. The family environment is central to the child's bio-psycho-social functioning.

Potentially destructive patterns of family adjustment to stress and illness have been described. Identification of these patterns and features of the disease which cause the family particular distress could guide anticipatory counseling. This study will explore the mother's view of her family relationships and activities when the child is chronically ill. The findings will describe the nature of these changes and the difficulties they present. The intent is to add new information on the mother's role, pattern of adjustment, and view of problem areas. Data relevant to changes in her relationships with the children and father
may furnish clues to their adaptation. Results of this study may provide a knowledge base for nursing intervention of families having a child with chronic respiratory disease and, subsequently, the development of a family assessment tool. Thus, the nurse may be helped to promote successful adaptation for all family members.

Conceptual Framework

The family can be viewed as a social system whose whole is greater than the sum of its parts. According to Allport (1960:301), an open system is characterized by "intake and output of matter and energy; the achievement and maintenance of steady states; generally an increase in order over time; and extensive transaction within the environment." Change in a part produces change in the whole, although this is not necessarily a direct relationship.

Within the family, each member occupies roles, defined as sets of prescribed behaviors for certain positions. These roles exist in dyads or pairs (mother-wife, etc.). Sets of rules govern role behavior and maintain some order over the group of relationships.

The nuclear family is generally seen as the basic unit of kinship organization in modern America. This unit consists of mother, father, and their children. Vincent (1963) warns against overemphasis on the isolation of the nuclear family, stating that members of the extended family
participate in the illness situation more frequently than is usually recognized. While this may be true, the nuclear organization alone is considered sufficient to constitute a "family."

In this study, chronic illness acts as an independent variable affecting the structure and function of the family. Illness is not a norm in today's society. Whether the illness has an insidious onset or the doctor's diagnosis is completely unexpected, illness introduces change to the family. As a result of this unusual event, the family system's steady state functions require reorganization. The ill member moves into a "sick role." Expectations and role behaviors shift to accommodate to the new situation (Shindall, Salloway, and Oberumpt, 1976:28; King, 1969:11; Olsen, 1970:170; Hill, 1958:146).

The changes imposed by illness can be differentiated from those which occur normally over a period of time. The family is dynamic and constantly evolving. Sometimes the system adjusts in response to routine problems. The deviant nature of illness, however, is associated with unusual problems. This introduces the concept of stress.

Illness leads to a tension state of stress. Burr (1973:201) attempted to define the nature and consequences of events producing change for the family and proposed, "... the stressor event is an event producing change in the family social system. Anything that changes some part
of the system such as the boundaries, structure, goals, processes, role, or values . . ." can produce some crisis or disruption.

Hill (1958:146) described the family's roller coaster response to a stressor event. After a state of shock, the family is plunged into a period of disorganization. Old role performances are ineffectual for the altered situation. "There follows a downward slump in organization, roles are played with less enthusiasm, resentments are smothered or expressed, conflicts are expressed or converted into tensions that make for strained relations." As the family learns successful adjustment, by trial-and-error or planning, a recovery prevails. When new roles and rules are set in response to the current needs of the system, a level of reorganization is formed. The reorganization may be better or worse than the one before.

The level of reorganization corresponds to the family's adjustment to a member's illness. Among the factors influencing level or reorganization are hardship of the event and the definition each member makes in regard to the seriousness of the changes wrought (Burr, 1973:202-203).

A child's chronic respiratory disease presents unusual problems for the family. When the child assumes the sick role, old expectations and sets of role behaviors are no longer valid. Changes in the family social system result as reorganization is attempted. Thus, by definition, the
child's disease becomes a stressor event. There is potential for disruption. The reorganized or regenerated family system may function as well as, better, or worse than, the previous organization. The family member's description of the changes that occur and the severity of these changes could provide information on level of reorganization and family functioning. In this study, the focus is on one family member, the mother, and her views of change affecting her activities and relationships when the child's diagnosed illness acts as a stressor.
CHAPTER 2

REVIEW OF THE LITERATURE

Review of the literature describes patterns of family response to illness. Some potential problem areas have been identified. The review will be presented as general factors of family response to stress and illness, emotional response to the child's illness, the mother and the treatment program, illness affecting the mother's daily activities, illness affecting the mother-sick child relationship, and illness affecting the mother-father relationship.

Family Response to Stress and Illness

Several authors have attempted to delineate variables affecting family response to stressor events (Burr, 1973:199-217). Olsen (1970:170-171) summarized characteristics of families likely to make a successful adjustment to stress and change.

1. There is a clear separation of generations so that the parents are satisfying each other's emotional needs or, in case of conflict, are able to fight straight. The important point is that they are not dealing with each other or satisfying inappropriate needs through their children.

2. There is flexibility within and between roles so that shifting can be tolerated with relative comfort. . . . The relative switch in roles does not result in chaos in the family.
3. There is tolerance for individuation. The family can accept and enjoy differences and can tolerate the anxiety of disequilibrium in the system as the members grow and change.

4. Communications among family members are direct and tend to confirm the self-esteem of each.

Gilhooley (as cited in Callahan and others, 1966:890) retained a sociological emphasis when discussing that reactions of other members to a patient's illness "... are determined by their attitudes toward a sickness, their feelings about the patient, the patient's role in the family, the prognosis and possibility of maintaining the patient's status in the group."

Dealing more specifically with the psychological impact of long-term childhood illness, Mattsson (1972:802-803) proposed that malaise, pain, physical symptoms, reason for illness, hospital admission, nursing, treatment procedures, and changes in emotional climate were significant variables.

Steinhauer, Mushin, and Rae-Grant (1974:830-832) speculated about the following factors of family response: the severity of the illness, the likely prognosis, the availability of an effective treatment, whether the disease is congenital or acquired, the age of onset of illness, the age of diagnosis, presence of pre-existing emotional disturbance within the family, the nature and results of the illness itself, effects of program of home management and restrictions on family life, presence or absence of other
affected siblings, repeated hospitalizations and surgical procedures, and cost of illness.

Travis (1976:43) theorized about the problem of family adjustment in terms of degree and manner of burden to the family, degree of financial burden, need for housing adaptation, pain, social isolation and unpredictability of crises, difference in school experience, factors affecting the manner of death, family size and structure, and relationships within the family.

Meyerowitz and Kaplan (1967:250-251) take the example of cystic fibrosis when explaining factors to be considered when assessing the impact of the disease on the family.

... The etiology of the disease is genetic and might therefore be expected to have implications for punitive response by family members; the bulk of the required treatment is administered in the home thereby requiring adjustment to the physical presence of the patient; therapy requires the cooperation of other members of the family which might be expected to influence familial role functioning; cystic fibrosis strikes the very young children and therefore increases the possibility of younger families, perhaps with fewer available resources, being forced to deal with a critical situation.

While many variables of family response to illness exist, common patterns of stress and adjustment may emerge. One level of reaction to illness is emotional.
Emotional Reactions

The child's illness has disruptive components as each family member responds with an affective reaction. Several sources report emotional response to the child's illness similar to Lindemann's (1944) classic description of grief and mourning, especially at time of diagnosis (Tiszda, 1962; Burton, 1973; Meyerowitz and Kaplan, 1967; Mattsson, 1972; Steinhauer and others, 1974; Kulczycki, Robinson, and Berg, 1969; Farkas and Schnell, 1973). McCollum and Gibson (1970:574) found that long term adjustment (to cystic fibrosis) was "characterized by a fluctuating balance between mourning and denial of diagnosis."

McCrae et al. (1973) discovered frequent admissions of guilt in CF parents. Seventy-nine per cent of mothers felt "run down or depressed," and 42% were under medical treatment which included antidepressant drugs. Lawler, Nakielny, and Wright (1966) identified that eight of eleven mothers of CF children were clinically depressed. Fathers exhibited an unusually high degree of psychopathy, including peptic ulcer, and all the CF children expressed depressive feelings. Tropauer, Franz, and Dilgard's (1970) study of 23 CF mothers revealed only three as being clinical depressed, but guilt and periodic discouragement were common. Boyle et al. (1976:324) investigated 27 adolescents and young adults with CF and concluded that, although most patients were "performing adequately, they showed excessive
anxiety and unexpressed anger, had poor self-images, and had difficulty compensating for their physical defects." Dubo et al. (1961) found frustration common to asthmatic children. In a study of 50 families in which a child had severe asthma, McLean, Schrager, and Stoeffler (1968) learned that parents in 14 families felt frustration and bewilderment.

The Mother and the Treatment Program

As the family attempts to deal with the illness on an emotional level, the mother traditionally assumes most of the burden of the home care (Travis, 1976:174-180; Burton, 1975:81-83; Sultz et al., 1972:214).

The mother has to watch the child's diet, supervise the medication, curtail his activities, and she also has to handle the child's own emotional reactions to the limitations and deprivations imposed upon him by his illness. At the same time, the mother has to deal with the siblings' reactions and guard against excessive involvement with the sick child to the detriment of her other relationships (Tiszda, 1962:57).

Certain features of the treatment program are likely to be unpleasant, leading to a conflict of wills between mother and child. Percussion and drainage was the greatest source of trouble for one group, in which 77% of children protested the treatment and 51% of parents disliked giving it (Burton, 1975). For each aspect of the treatment program, there was found "... a close relationship between attitudes of both parents and children, and undoubtedly the
attitudes of one modified and altered the attitudes of the other" (Burton, 1975:96).

It can also be seen that a treatment program absorbing much of the mother's time could leave her with little energy or leisure time. "Because of this the mother's own emotional resources may be depleted and she may find it increasingly difficult to be happy and positive with all her family" (Burton, 1973:248). Timing of the treatments could create scheduling problems with other activities. McCollum and Gibson (1970) found household routines frequently interrupted for treatment. Family routines were felt to have become "quite complicated" or "very difficult" for 96% of the CF families studied by Meyerowitz and Kaplan (1967:252).

Identification and eradication of allergies in the asthmatic child's diet may be quite difficult for the mother. Diagnosing which food causes the attack may take a long time, much experimentation, and shrewd observation. The shifting nature of allergens frustrates the family. . . . Mothers who work, or who have many children, and are unable to devote all their time to supervision of one child meet defeat in keeping the allergic child from even those foods she herself knows will cause him to have an attack (Travis, 1976:178).

Thirty-five per cent of the asthmatic children in the study by Sultz et al. (1972:214) were on special diets.
Illness Affecting the Mother's Daily Activities

The nature of the child's disease and treatment program affects the mother's daily activities. One example of such a change is housework. Fifty per cent of asthmatic families and 35% of cystic fibrosis families experienced a change in housework, according to Sultz et al. (1972). For asthmatic families, this change was an increase in housework in an attempt to reduce dust and mold. Burton (1975:124) discovered that many CF mothers found a release in work; "mothers were temporarily enabled to overcome their depression or forget some of their responsibilities." Mothers of CF children viewed housework as secondary to child care, and any lapse in their chores was compensated by help from family and friends (Burton, 1975:122-123).

Meyerowitz and Kaplan (1967) learned that the incidence of working mothers in their sample dropped from 54% to 26% following a diagnosis of CF, probably indicating that many mothers were participating in time-consuming treatment programs. Research reveals that actual severity of the child's illness is not a deciding factor in the mother's decision to work. An interesting hypothesis is that a working mother reflects the mother's search for gratification outside the home, rather than in an overly protective relationship with the sick child. This situation allows the child more autonomy. Seventy per cent of adolescents...
that were functioning well in the Boyle et al. (1976) study had working mothers.

A mother's limited contact outside the home may produce social isolation. Some reasons for the mother's reduced outside activities are: fear of the child's exposure to allergens, infection, and aggravating weather conditions; a sense of distrust and alienation of outsiders; and limited time and energy (McCollum and Gibson, 1970:575; McLean et al., 1968; Ferrara, 1969; Turk, 1964; Steinhauer et al., 1974; Meyerowitz and Kaplan, 1967).

Twenty-eight per cent of asthmatic parents and 13% of CF parents in one source reported a decrease in social activity (Sultz et al., 1972). Elsewhere, half of the CF families interviewed "drastically" reduced social activity (Kulczycki et al., 1969:323). Similarly, half of the families in McLean et al.'s (1968) research were restricted in family activities because the asthmatic child could not participate. Turk (1964) revealed that CF parents felt deprived of time and energy for family leisure and adult activities.

As a result of the child's illness, the mother's sleep is frequently disturbed. Of the children that McCollum and Gibson (1970) studied, 59% had sleep disturbances which usually woke the parents. In response to the CF child's various sleep problems, 56% of the parents told Burton (1975) that they allowed the child to sleep in their
bed at night. Turk (1964:69) also found a large percentage of CF children sleeping in the same room as the parents.

Asthma can also affect the family's pattern of sleep. Asthmatic attacks frequently occur in the middle of the night, with the mother usually going to care for the child (Travis, 1976:167-175 passim). Thirty-seven of the 50 McLean et al. (1968:1223) families stated that the child's asthma resulted in their loss of sleep. At least one hour of sleep was missed each night for 18 of these families.

**Mother-Sick Child Relationship**

The pattern of interaction between mother and sick child can be profoundly influenced by the illness. Two dysfunctional models of mother-child relationships emerge: overprotection and rejection/denial. Overprotection results in an overly strong symbiotic relationship between parent and child, limiting the child's opportunity for independence. A typical pattern is dominant mother, sick child, and passive remote father (Grossman, 1975; Geiger, 1974; London, 1970; Travis, 1976:175-196 passim; Burton, 1975; Pinkerton, 1972; Shannon, 1961; Tiszda, 1962:55; Mattsson, 1972; Meyerowitz and Kaplan, 1967; Boyle et al., 1976; Tropauer et al., 1970; McCollum and Gibson, 1970). Parental overprotection and fear can develop into the vulnerable child syndrome, in which the child responds to the parent's
attitudes and tacit belief in his probable death (Green and Solnit, 1964).

A second and less common group of aberrant parental response to the child's illness is "... rejection or neglect of a disabled child and ... extreme denial of the severity of the illness" (Mattsson, 1972:807). Pachacki (1976:191-192) noted that the child with severe, emotionally triggered asthma was invariably undesired or undesirable in some way. Pinkerton (1972:434) asserts that parental intolerance of the child's asthma could well have an antecedent basis and "the particular danger in these cases is that parental non-acceptance may evoke an attitude of denial by the patient in his desperate bid to retain family approval so that both child and parent are blinded to the hazard of attempting to 'shrug off' serious disability." Closely related to parental rejection is a strong system of denial which erodes compliance with the treatment program (Rosenlund and Lustig, 1973:960; Mattsson, 1972:807-808; Tropauer et al., 1970; Burton, 1975:86-91; Steinhauer et al., 1974).

Accordingly, the mother's ideas of child-rearing and discipline may be altered. A "double standard" of discipline for the sick child and his well siblings developed in 60% of asthmatic families because the parents were afraid of precipitating an attack. As a result, parents felt manipulated, frustrated, and guilty (McLean et al., 1968:1223).
Generally, overprotective mothers have difficulty setting limits for the sick child (Rosenlund and Lustig, 1973; Grossman, 1975; Green and Solnit, 1964).

This subject was pursued in some depth by Burton (1975:140-146). Only 30% of families treated the cystic child as normal. A conflict between protection and fostering independence led 44% of parents to feel unhappy with their care of the child. Sometimes the child was treated normally when well, with extra allowances made when the child was sick. Forty-six per cent of parents were less likely to punish the child, and 67% of parents of preschool children were guilty and unhappy after the punishment.

Parents often increase the supervision of the sick child (Boyle et al., 1976; Mattsson, 1972:807; McLean et al., 1968). This was true for 47% of parents in one study (McCollum and Gibson, 1970:575). Meyerowitz and Kaplan (1967:255) reported that parental anxiety rose with the amount of the child's outside activity and sports.

Another dimension of maternal protection may lead to her reluctance to relinquish the child's care to another, thus limiting her social activity. Parents who reported that they went out socially without the child were more likely to manifest psychosomatic symptoms, possibly indicating guilt or anxiety (Meyerowitz and Kaplan, 1967:258).
The child's health may affect his behavior toward the mother (Travis, 1976:187-189). Feeding problems are common in young children with CF; voracious appetite and failure to thrive are noted. Occurring in infancy, this had serious effects on the mother-child bond (Burton, 1975:26-27; McCollum and Gibson, 1970:575). Seventeen of 50 families admitted that the asthmatic child was irritable when sick. "Whining, complaining, and aggressive behavior directed at others . . . made them unpopular and to be avoided when symptomatic. The ensuing social isolation of the asthmatic child in turn may produce additional anger and guilt on the part of other members of the family social system" (McLean et al., 1968:1223). Excessive dependency is frequently mentioned (Boyle et al., 1976; Tropauer et al., 1970; Grossman, 1975:832). The child may seem timid and fear abandonment (Burton, 1975).

Mother-Sibling Relationship

It might be thought that the demands of the sick child would reduce the amount of time the mother spends with the well siblings (Burton, 1975:190; Grossman, 1975:832). Thirty-six per cent of asthmatic families said the siblings resented this extra attention (McLean et al., 1968:1223). Thirty-nine per cent of cystic fibrosis motheres reported the siblings felt "left out" or "resentful" (Burton, 1975:192-193).
Sibling jealousy might also result in behavior problems (Steinhauer et al., 1974:835). One source stated: "School adjustment difficulties, learning problems, and delinquency in siblings were attributed by both patients and their mothers to the strain imposed by the chronic illness and its aggravating effect on family rivalries" (Tropauer et al., 1970:430). These changes in the sibling's behavior may or may not produce stress for the mother and affect her relationships with the well children. Burton's (1975) parents reported many forms of sibling's attention-getting behavior, but surprisingly did not see this as a real problem for them. While CF mothers studied by Turk (1964:70) worried about the sibling's behavior, "they failed to come to grips with problems of the other children, stating 'we will give attention to them later.'"

The mother's communication with the well siblings about the disease is another indicator of adjustment. Burton (1975:200-202) learned that over 53% of CF mothers never mentioned the illness to the well siblings. When it was discussed, the mother usually provided evasive and/or limited information. Turk (1964:70) found that a "web of silence" about CF prevailed, and the reasons for restrictions were seldom explained to the siblings. The adaptive mechanism of denial is apparently at odds with open communication. Well siblings' knowledge of the diagnosis of CF has
been associated with stress for the parents (Meyerowitz and Kaplan, 1967:260).

**Mother-Father Relationship**

Minuchin et al. (1975) studied transactional patterns of family responses to conflict and stress. Three patterns—triangulation, parent-child coalition, and detouring—emerged as coping mechanisms. While any family may resort to these patterns, those functioning poorly may use them to the exclusion of more healthy methods of conflict resolution.

In the first two patterns, triangulation and parent-child coalitions, the spouse dyad is frankly split. In triangulation, the child is put in such a position that he cannot express himself without siding with one parent against the other. In the second pattern, parent-child coalition, the child tends to move into a stable coalition with one parent against the other. The role of the excluded parent varies to the degree that he tries to disrupt the coalition. In the third type of pattern, called detouring, the spouse dyad is united. The parents submerge their conflicts in a posture of protecting or blaming their sick child, which is defined as the only family problem (Minuchin et al., 1975:1034).

Spouse communication is often limited. In 18 of 25 cystic fibrosis families studied by Boyle et al. (1976), communication between parents was inadequate. In Burton's (1975) population, 16% of mothers and 25% of fathers felt unable to fully discuss the disease with their spouse. Cystic fibrosis mothers complained to Tropauer et al. (1970) that fathers didn't share their feelings. Kulczycki et al.
(1969) described "varying degrees of discomfort" in parental communication of CF. Turk (1964) found that CF parents avoided discussion of family planning, as did McCrae et al. (1973). Sultz et al. (1972) found this topic was a source of conflict for CF parents.

At times the extra burdens of the child's disease are detrimental to the spouse relationship. In the parent-child coalition mentioned before, the mother may enter an intense relationship with the sick child, leaving the father on the periphery. Lawler et al. (1966) related that marital relations were "severely strained" in their sample. Boyle et al. (1976) and McCrae et al. (1973) also indicated that some marriages were troubled, although this incidence may not have been greater than that for the general population.

One factor commonly assessed is whether the illness had strengthened or weakened the marital relationship. Mattsson (1972:808) believed that response to this question was tempered by rationalization.

One commonly hears from parents of chronically ill children that the disorder has enriched the whole family, both emotionally and spiritually, and has developed their sense of compassion and tolerance. While indeed there may be some truth in such statements, these attitudes assist the parents in hiding from themselves sad and resentful effects related to their unique burden.

When Sultz et al. (1972:213) asked this question of asthmatic parents, 35% felt the marital relationship was closer, 15% weaker, and 50% the same. McCrae et al. (1973)
learned most of the CF couples thought their relationship was unaffected or strengthened. In Burton's (1975) study, 64% of mothers and 53% of fathers felt the illness had strengthened the marital relationship.

Finally, the child's illness may decrease the number of parent activities. Turk (1964) found parents deprived of time to be alone together and time and energy for adult activities.

Summary

This chapter offers a review of the literature pertinent to the research problem. Further chapters will describe the methodology; present the data; discuss the findings in relation to the review of the literature, conceptual framework, and nursing implications; and summarize the study.
CHAPTER 3

METHODOLOGY

This study explored the mother's views of selected changes in her family activities and relationships when her child has chronic respiratory disease. Both the nature of the change due to the child's illness and the degree of hardship these changes represent were investigated. The following aspects of the study will be discussed in this chapter: study design, sample population, interview schedule, human subjects requirements, data collection, and data analysis.

Design of the Study

An exploratory type of design was chosen to generate insights to the above situation, in order to allow for flexibility and provide optimum opportunity for identifying details in family behavior pertinent to the study question. An interview schedule was developed to elicit the mother's view of change in the child's care and family structure. This schedule guided a semi-structured interview with nineteen mothers of children with chronic respiratory disease. Results of this study will provide additional information for further development of a family assessment tool.

26
Sample Population

The target population consisted of English-speaking mothers of chronically ill children. Children in the pre-school category, between one and six years of age, were sought in order to obtain a group with similar developmental characteristics. It was further stipulated that the children must: (1) live in the same home with the mother, (2) have been diagnosed as having a chronic respiratory disease, (3) have been seen at a university medical center's respiratory or allergy clinic. An attending physician asked that a group of cystic fibrosis families recently transferred from a clinic at a different location not be contacted. For this reason, CF mothers were excluded from the final study.

Interview Schedule

An interview schedule was developed for this study (see Appendix A). Content of the schedule was derived from factors deemed significant following a review of the literature and consultation with colleagues. The topics were not meant to be exhaustive to avoid a lengthy interview session. Instead, areas examined were those found important by previous investigation and those within the realm of the mother's experience. The areas are: (A) general information, (B) the treatment program, (C) the mother's daily activities, (D) mother-sick child relationship,
(E) mother-sibling relationship, and (F) mother-father relationship. Questions B8 and B9, asking if there was any aspect of the whole treatment program that the sick child protested or resisted or the mother disliked, were specifically suggested by Burton (1975).

All the questions in the final version of the interview schedule were pretested with a mother of a cystic child and a mother of a child with atypical Goodpasture's Disease. Since the length of the interview session exceeded forty-five minutes, six relatively unproductive questions were eliminated. One deleted question asked about the child's hospitalizations in the last six months. This question contained many variables (time, length of illness, reason), and it was thought relating this information to patterns of long term adjustment to chronic illness would not be generally gainful. For each of the sections on treatment program, mother's daily activities, mother-sick child relationship, mother-sibling relationship, and mother-father relationship, the mother was asked, "What aspect of change has been the easiest?" These questions were also eliminated, as the mothers spent a good deal of time pondering them and still were unable to provide answers.

Of the questions that were retained, construct validity for categories was checked by having a clinical specialist in pediatric pulmonary nursing sort the responses of three mothers. There was 100% agreement of assignment
for nineteen questions. Sixty per cent agreement of assignment was achieved for the three questions dealing with diet, change in mother's activities outside the home, and aspects of the treatment program the child protested or resisted.

Ratio scales were developed for questions asking for a magnitude response to provide quantitative data and the opportunity to use relatively powerful statistical analysis. (Equal intervals were assumed.) For each of several questions, a 3 x 5 card was presented to the mother. She was asked to indicate a point on a ratio scale which best described the situation. The scale for the question (B4) of difficulty scheduling medicines and treatments to fit in with regular family routines appeared:

```
0 1 2 3 4
not extremely
difficult
difficult
```

Identical cards were presented for questions of difficulty for treatment program as a whole (B12), difficulty of side effects of medication (B8), difficulty of change in mother's daily activities (C8), difficulty of changes in mother-sick child relationship (D6), difficulty of changes in mother-sibling relationship (E5), and difficulty of changes in mother-father relationship (F5).
The card presented for the question which asked how often the mother slept in the same room with the child (C6) had the following scale:

\[
\begin{array}{cccccc}
0 & 1 & 2 & 3 & 4 \\
\text{never} & & & & \text{always}
\end{array}
\]

The card presented for the question which asked how free the mother felt to fully discuss the child's illness and its problems with the father (F2) had this scale:

\[
\begin{array}{cccccc}
0 & 1 & 2 & 3 & 4 \\
\text{not free} & & & & \text{extremely free}
\end{array}
\]

**Protection of Human Subjects**

Procedures for assurance of protection of the rights of human subjects were in accordance with Health, Education and Welfare guidelines. Permission for the study was obtained from the Human Subjects Committee. It was felt that the potential for risk was small. If, however, the subject had experienced distress, the interviewer (a nurse) was prepared to cope with the situation. Possible benefits for the mother included the opportunity to discuss her concerns with a nurse, ask questions, and receive appropriate referrals. The subject's consent form used is presented in Appendix B.
Data Collection

Permission to conduct the study was received from the director of the medical center chest and allergy clinic and the three attending pediatricians associated with the clinic. Lists of families meeting the study criteria were then provided by clinic staff. This list of potential subjects was narrowed to those mothers who could be interviewed in the metropolitan area. A letter was sent to these prospective subjects, briefly describing the purpose and nature of the study (see Appendix C). The letter was followed by a telephone call to the mother. If the mother agreed to participate, the researcher made an appointment for an interview. Many families had relocated, and it was sometimes difficult to obtain current telephone numbers and addresses. Once contact was made, however, most mothers were willing to participate. The two mothers who were not stated that their children were not sick. Interviews were hard to schedule for three working mothers. The study population consisted of the first nineteen mothers who agreed to participate and were readily available for interview.

Data Analysis

After the data were collected, categories of response for nominal data were formulated. These categories were not mutually exclusive. Mothers could give more than
one answer to a question. The study was concerned with kinds of responses of the mothers as a group.

Coding continued for all responses, followed by tabulation. Statistical analysis was selected according to the nature of the data. Frequency, percentage, and modes were found for nominal data. Yule's $Q$ (Mueller and Schuessler, 1961:242-249) and lambda (Freeman, 1968:71-78) were calculated for association between nominal data. Symmetric lambda was used unless otherwise indicated. Ranges, means, Student's $t$ (Downie and Heath, 1965:138-144), and Pearson's $r$ (Freeman, 1968:89-107) were found for interval level data.

**Summary**

This chapter deals with the following aspects of the research methodology: study design, sample population, interview schedule, human subjects requirements, data collection, and data analysis. Further chapters present the analyzed data.
CHAPTER 4

PRESENTATION OF THE DATA

The mother's views of selected changes in her family activities and relationships were explored using an inter­view schedule. This chapter presents the characteristics of the sample and the research findings. Analysis of the data, nursing implications, and recommendations for further study are discussed in following chapters.

Appendix A contains frequencies, central tendencies, and dispersions of the data, including scales. Correlations and other figures were judged statistically significant if p < .05, and substantively significant if p < .1.

Characteristics of the Sample

The sample population consisted of nineteen mothers of children with chronic respiratory disease. Thirteen of these children were male, six female. Fourteen were Anglo, four Mexican-American, and one black. Patients ranged in age from fifteen months to sixty months, with a mean of 43.7 months.

The mothers ranged in ages from 25 to 56 years, with a mean of 32.2 years. In one case, the mother figure was in actuality the maternal grandmother. The one foster mother
had cared for the child three and one-half years. Thirteen mothers were Anglo, four Mexican-American, and two black.

The Child's Illness

Mothers reported "asthma" as a definite diagnosis in fourteen cases (74%) and a probability in four others (21%). The one mother who ruled out asthma as a possible diagnosis --"bronchopulmonary dysplasia and allergies" was the response--was herself an asthmatic with many allergies. Additional diagnoses given were "trach," "chronic lung disease with blebs," "allergies," and "repeated viral pneumonia with right lung collapse." Three mothers replied that they did not know the definite cause of the child's illness, stating "they never told us."

At the time of the interview, all of the children had been sick at least six months. The mean duration of illness was 29.7 months. Histories of the course of the illness fell into two categories. In one category, typically, the child became ill and the diagnosis of a chronic condition was soon established (n = 12 ill before diagnosis < 3 months; n = 13 ill before diagnosis < 6 months). Three of the children were born prematurely, one of whom waited six months for diagnosis. A representative comment of this first category was "One day I had a healthy child, and the next he had asthma and was in the hospital."

In the second category (n = 6), there was an average of
23.7 months between onset of symptoms and diagnosis. Four of these mothers had noticed symptoms of eczema and/or relatively minor respiratory allergies in the younger child. Repeated hospitalizations had been required by the remaining two children.

Thirteen mothers (68%) described crisis situations occurring at some time during the child's illness. One mother said:

I felt every emotion. I looked at this child suffering and thought, "Why did I ever have children?" . . . [and] I was angry with him for being so sick. I thought, "Why did this have to happen to me?"

Another revealed: "When [patient] became ill, I was very depressed. I didn't think I'd ever not be depressed."

There was often a difficult search for the correct treatment. One woman explained her feelings during a protracted crisis situation.

He was hospitalized three times in six months. The first time I was O.K. I felt the doctor would just fix things. The second time it was worse. The third time I was really afraid. I didn't think his doctor knew what he was doing.

Eleven mothers (58%) had feared for the life of their children, setting the stage for the "vulnerable child syndrome" described by Green and Solnit (1964).

By the time of the interview, mothers were in the stage of long term adjustment to the child's illness and most had passed the crisis. Many children had been severely ill but were now much improved. The child's symptoms were
episodic, with acute attacks occurring with variable severity and frequency. With at least a partial reduction in medications, treatments, and attacks, the mothers found "it's much easier now." One mother rated her child's health as excellent, eleven as good, four fair, and two poor. A frequent comment was that the child "has fewer colds" than his siblings or the neighbor children.

The Treatment Program

All parameters of the treatment program were identified by the mother as her responsibility. Clearly the maintenance of the child's health was felt by the mother to be one of her important family roles. Mothers' reports indicated that others also perceived this to be her role (husband, mother-in-law, doctor).

Diet

In response to the question, "Is there anything that you especially try to include in his diet or anything that you leave out?", no mother mentioned increased fluids, although two mothers did so at another point in the interview. Table 1 shows the children's diet restrictions. Six children were prohibited milk and milk products, and two younger children were on Isomil. One mother eliminated milk only "when he has asthma." Only two mothers reported current major restrictions in the child's diet. Diet restrictions were not mentioned as aspects of the treatment program that
Table 1. Types of Diet$^a$ (N=19)

<table>
<thead>
<tr>
<th>Types of Diet</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>9</td>
<td>47.4</td>
</tr>
<tr>
<td>Milk free</td>
<td>8</td>
<td>42.1</td>
</tr>
<tr>
<td>Multiple restrictions</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Minor restrictions (chocolate, milk)</td>
<td>2</td>
<td>10.5</td>
</tr>
</tbody>
</table>

$^a$Subjects could choose more than one option.

either the child or the mother disliked. Only one mother identified diet as a most difficult aspect of change (for herself).

Medicines and Treatments

Most of the sick children's medicines were bronchodilators or antihistamines. The average number of medicines given to the child was 2.5. Frequency of administration varied, as many of the medicines were p.r.n. Table 2 shows the children's treatments.

All of the nine mothers (47%) who reported that maintenance or cleaning of equipment was necessary took care of this, and only spent "a few minutes" per day doing it. The equipment and supplies necessary for one child—oxygen tanks in the home and car, suction machine, new trach tubes,
Table 2. Types of Treatment\(^a\) (N=19)

<table>
<thead>
<tr>
<th>Types of Treatment</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>7</td>
<td>36.7</td>
</tr>
<tr>
<td>Vaporizor</td>
<td>7</td>
<td>36.7</td>
</tr>
<tr>
<td>Percussion and drainage</td>
<td>5</td>
<td>26.3</td>
</tr>
<tr>
<td>Aerosol</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Suctioning</td>
<td>1</td>
<td>5.3</td>
</tr>
</tbody>
</table>

\(^a\)Subjects could choose more than one option.

trach ties, suction catheters, saline, and Betadine—were "sometimes a problem." A fair amount of planning was necessary, as many supplies required a prescription and the source was located some distance away from the family's home.

Sixteen mothers (84%) reported that only "a few minutes" per day were regularly spent on medicines and treatments, two mothers 20-30 minutes a day, and one mother 30 minutes four times a day. One mother explained, "It's not long, it's just inconvenient--always when you're doing something else." When a child became congested, time-consuming aerosol and percussion and drainage treatments were begun and medication given more frequently.

The mothers indicated that scheduling medicines and treatment to fit in with regular family activities was
relatively easy (mean = 1.10, see Appendix A). In all cases, the mother was identified as responsible for the supervision of medicines and treatments. In two families, the mother and father shared the supervision. One maternal grandmother assumed the responsibility while the mother was at work. This was the only case in which primary responsibility was not the mother's.

Nine mothers (47%) noticed side effects of medication, with an additional four (21%) reporting side effects in the past. The most common side effects were hyperactivity (n = 7) and nausea and vomiting (n = 5), as seen in Table 3. Other side effects reported once were: hypertension associated with prednisone, drowsiness, constipation, false sense of nasal discharge, local tissue reaction from adrenalin shots, and large size. The incidence of side effects was not associated with any particular medicine, but hyperactivity rose with increased dosages. Side effects of medications presented a problem, indicated by a mean difficulty rating of 2.29 and a range of .5 to 4.0.

Treatment Program as a Whole

Seventy-nine per cent of the children protested or disliked some intrusive aspect of the treatment program. Table 4 shows those aspects of the treatment program as a whole that the children protested or resisted. Medication accounted for most of the resistance: 7 children (37%)
Table 3. Side Effects of Medication\textsuperscript{a} (N=19)

<table>
<thead>
<tr>
<th>Side Effects</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity</td>
<td>7</td>
<td>36.8</td>
</tr>
<tr>
<td>None</td>
<td>6</td>
<td>31.6</td>
</tr>
<tr>
<td>Nausea &amp; vomiting</td>
<td>5</td>
<td>26.3</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>21.1</td>
</tr>
</tbody>
</table>

\textsuperscript{a} Subjects could choose more than one option.

Table 4. Aspects of the Treatment Program that the Child Protested or Resisted\textsuperscript{a} (N=19)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine</td>
<td>7</td>
<td>36.8</td>
</tr>
<tr>
<td>Shots</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Aerosol</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Percussion and drainage</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Doctor</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Hospital</td>
<td>1</td>
<td>5.3</td>
</tr>
<tr>
<td>Ointment</td>
<td>1</td>
<td>5.3</td>
</tr>
<tr>
<td>Suctioning and changing trach</td>
<td>1</td>
<td>5.3</td>
</tr>
</tbody>
</table>

\textsuperscript{a} Subjects could choose more than one option.
disliked the p.o. medication, 4 (21%) shots, and 1 (5%) her
ointment. Six mothers (32%) noted that the child was less
cooperative with medicines, shots, and treatments as he
became older. One mother explained that this was because
the potency of the shots had increased, and two others said
that frequency had decreased and the child was no longer
"used to it all the time." As seen in Table 5, there was a
very strong association between child protest of medicine
and side effects of nausea and vomiting, and little associa-
tion between child protest of medicine and side effects of
hyperactivity (Yule's Q = .82 and .20, respectively).

Table 5. Association Between Most Frequently Reported Side
Effects of Medicine and Incidence of Child Protest
and Mother Dislike of Medicinea

<table>
<thead>
<tr>
<th></th>
<th>Child Protest Medicine</th>
<th>Mother Dislike Medicine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea &amp; vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=5</td>
<td>.82</td>
<td>.73</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=7</td>
<td>.20</td>
<td>.78</td>
</tr>
</tbody>
</table>

aValues in cells are Yule's Q's.
Aspects of the whole treatment program that the mothers disliked are shown in Table 6. Thirty-seven percent of the mothers (n = 7) could not think of anything they disliked. On the other hand, three mothers replied with general statements of "I don't like any of it" and "I do worry." A recurrent concern was the unnatural aspect of maintaining the child on medicines (n = 4, 21%). Doctor and clinic visits were disliked because the family lived a distance away (n = 3) and visits consumed time (n = 3). One mother said, "I have to get a ride from neighbors. Instead of bringing her to the hospital, I try calling the doctor and seeing how she does with the medicine." Other disliked aspects of the treatment program were "changing the trach," and "staying up at night to see that she clears for sure [after the medicine]. Sometimes I go back to bed sooner than I should." Side effects of both hyperactivity and nausea and vomiting were strongly associated with higher incidence of mother disliking medication, as seen in Table 5 (Yule's Q = .78 and .73, respectively).

Allergy shots were a mixed blessing to asthmatic families. Six mothers volunteered that shots had improved their child's health. After months of searching for effective treatment, allergy shots seemed a useful weapon against the illness. There were no differences in the scores for treatment program difficulty, whether or not the children received shots. However, there were strong positive
Table 6. Aspects of the Treatment Program that Mothers Disliked$^a$ (N=19)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>7</td>
<td>36.8</td>
</tr>
<tr>
<td>Unnatural aspects of medicine</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Doctor (distance)</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Doctor (time)</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>General dislike and worry</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>15.8</td>
</tr>
</tbody>
</table>

$^a$Subjects could choose more than one option.

associations between allergy shots and mothers' dislike of doctor visits (Yule's $Q = .94$) and allergy shots and child protest of shots (Yule's $Q = .82$).

Table 7 indicates the most difficult aspects of the treatment program. The largest group, 31.6%, found matters of vigilance the most difficult: "keeping him quiet and rested," "making sure he gets everything that he needs," "getting up at night," etc. One group of mothers mentioned testing (n = 4), another "keeping up with doctor's visits" (n = 4), "if he has to go to the hospital" (mother's time; n = 2). Two mothers could think of no difficult aspect, saying, "It's much easier now—he doesn't get as sick as often." A mother was distressed because her daughter "won't let herself be examined. She cries and screams and kicks."
Table 7. Most Difficult Aspect of the Treatment Program\(^a\)
(N=19)

<table>
<thead>
<tr>
<th>Difficult aspect</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vigilance</td>
<td>6</td>
<td>31.6</td>
</tr>
<tr>
<td>Testing</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Doctor visits</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>10.5</td>
</tr>
</tbody>
</table>

\(^a\)Subjects could choose more than one option.

I don't know why." Another was disturbed by ". . . the artificial aspect of the trach. You see a hole in your child's neck . . . [and it makes] difficulties with his talking."

The treatment program was mildly difficult for most mothers, as indicated by a mean difficulty score of 1.34 (range = 0 to 4.0). Table 8 shows the correlations between difficulty scores for the whole treatment program and other selected variables. The correlation between length of illness and difficulty scores for treatment program was \(-.39\) (\(p < .10\)). This indicates that 16% of the variance in treatment program difficulty scores was negatively associated with length of illness. Statistically significant correlations (\(p < .05\)) were obtained for the correlations of
Table 8. Pearson's r for Difficulty Scores for the Treatment Program as a Whole and Selected Variables

<table>
<thead>
<tr>
<th>Difficulty Score for Program as a Whole</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty score medication side effects</td>
<td>.43*</td>
</tr>
<tr>
<td>Difficulty score scheduling medicines and treatments to fit in with regular family activities</td>
<td>.60*</td>
</tr>
<tr>
<td>Length of illness</td>
<td>-.39**</td>
</tr>
<tr>
<td>Child's age</td>
<td>-.33</td>
</tr>
<tr>
<td>Number of doctor and clinic visits in last 6 months</td>
<td>-.21</td>
</tr>
<tr>
<td>Mother's age</td>
<td>-.13</td>
</tr>
</tbody>
</table>

*Significant at .05 level.
**Significant at .1 level.

treatment program difficulty and difficulty scheduling medicines and treatments to fit in with regular family activities (r = .60), and treatment program difficulty and difficulty of side effects (r = .93). Thus, 36% of the variance of the treatment program difficulty scores can be explained by scores for scheduling treatments and medicines, and 87% by difficulty scores of medication side effects.

Mother's Daily Activities

The review of the literature suggested that having a sick child might lead the mother to alter her patterns of daily activities. Table 9 shows the number and percentage of mothers reporting change in various daily activities.
Table 9. Changes in Selected Daily Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>19</td>
<td>100.0</td>
</tr>
<tr>
<td>Outside activities</td>
<td>16</td>
<td>82.2</td>
</tr>
<tr>
<td>Housework</td>
<td>12</td>
<td>63.2</td>
</tr>
<tr>
<td>Choice to work</td>
<td>10</td>
<td>52.6</td>
</tr>
</tbody>
</table>

Work

Ten mothers (58%) retained the same employment status before and after onset of symptoms. No important association was seen between the child's health rating and mother's current job status (lambda = .26). Eight women felt that the child's illness would influence their choice to work, and another two had experienced this in the past. A strong negative association existed between child's health rating and the illness influencing the mother's choice to work (lambda = .72). Thus, knowledge of these variables eliminates 72% of the errors made in predicting one from the other.

Five women (26%) felt that the child's health was her job, stating "I took a year off . . . for her to settle down," "I quit because I'd rather get his health back," etc.
Four mothers (21%) thought there was no influence and did not elaborate, four (21%) saw caretaker problems "because no one is going to take care of him like me," three (16%) said "I have to work," and two (11%) saw day care problems "because she would be exposed to so many things." One mother (5%) said, "He drives me crazy, makes my nerves so bad I couldn't hold a job if I tried. I can't cope."

Housework

Most mothers reported changes in housework due to the child's illness. Nine mothers (47%) experienced an increase in housework, using such phrases as "tremendous change" and "an increase by 50,000,000 times." This reflected the effort to reduce dust and mold in the allergic child's environment. A healthy home for the child sometimes required considerable sacrifice for other family members.

Before the most difficult thing was the cleaning. I used to damp mop the whole house every day. We didn't have a book in the house, a picture on the wall. . . . My diabetes started up two years ago. I had no energy. I couldn't keep up with the cleaning. My husband would come home after working all day and mop the house.

Seven mothers (37%) felt the child's illness had not changed their housework. Three mothers (16%) performed less housework due to the time demands imposed by the sick child, "There are things I don't get done and leave for the next time."
Outside Activities

Eighty-four per cent (n = 16) of mothers described a decrease in their outside activities due to the child's illness. The situation seemed to be related to babysitting problems. Thirteen responses (68%) indicated that whole family activities were limited because of the sick child's susceptibilities. Six mothers (32%) elaborated that they could not go where allergens were present, two (11%) where risk of exposure to crowds was present, and two (11%) during cold or wet weather. Four mothers answered, "When he is sick, I just don't go." One said, "The illness has limited our budget. We don't go to as many movies as we used to."

Sleep

The biggest change in the mother's daily activities was seen in her sleep. All mothers reported a disruption in their sleeping patterns due to the child's illness. Seven (37%) said that they slept lighter, waking when the child coughed. Two mothers (11%) regularly checked on the sleeping child. One of these mothers reported, "At night I have to see how she is, to shake her."

Nearly all children got sicker at night, with the mother getting up to care for the sick child. Only one mother said she and her husband took turns caring for the child at night. Another couple had been forced to share night-time duties during one period of protracted illness:
We used to take turns staying up with her because I couldn't keep up. I couldn't always stay up with her and then work eight hours. It got to the point where I wasn't even emotionally stable because I didn't get any sleep.

Only one child slept in the same room with the mother more than half of the time. This was a single mother whose house had only one bedroom. Just one mother reported that sleeping with the sick child was a problem for the marriage now, and another in the past. This question was not very productive, as a more common pattern was the mother bringing the sick child into another room and staying up during the night.

Pearson's r for the association between mother's age and the frequency of mother and sick child sleeping in the same room together was -.41 (p < .10). This indicates that younger mothers were more likely to sleep in the same room with the sick child. Thus, 17% of the variance in sleeping together can be explained by the mother's age. No significant correlations were found for frequency of mother and child sleeping together and child's age, length of illness, number of doctor or clinic visits in the last six months, or difficulty scores for treatment program as a whole.

Summary

Responses to the question, "Which aspect of change in your daily activities has been the most difficult?" varied widely. These answers are found in Appendix D.
The mean difficulty score for changes in the mother's daily activities was 1.45, second only to that of medication side effects. One mother who scored a 3.0 for this question had severe babysitting problems and problems transporting equipment. She concluded, "It's easier to stay home. Everything has changed. There is a change on the whole household."

The question was asked whether change in a particular aspect of daily activities resulted in a higher difficulty score. Student's t was therefore calculated for difficulty scores of groups answering yes or no to questions of influence on choice to work, change in housework, and change in outside activities. No significant difference was found between groups of change/no change in housework, or change/no change in mother's outside activities. A significant variation was found for the two groups of influence/no influence on mother's choice to work (t = 21.05, t .05 = 2.11). Pearson's r showed no significant correlations for difficulty scores of mother's daily activities and mother's age, child's age, number of doctor and clinic visits in the last six months, or length of illness.

Mother-Sick Child Relationship

As the child moves into the sick role, this alters his/her role interactions with other family members. The mothers in this study acquired the role of guardian of the
child's health. Potential for change in the mother-sick child relationship was great. Table 10 shows the number and per cent of mothers reporting changes in their relationships with the sick children.

Table 10. Selected Changes in Relationship with Sick Child

<table>
<thead>
<tr>
<th>Change</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervision of child's activity</td>
<td>19</td>
<td>100.0</td>
</tr>
<tr>
<td>Thoughts of others caring for child</td>
<td>13</td>
<td>68.4</td>
</tr>
<tr>
<td>Child's behavior toward mother</td>
<td>12</td>
<td>63.1</td>
</tr>
<tr>
<td>Thoughts of child-rearing and discipline</td>
<td>8</td>
<td>42.1</td>
</tr>
</tbody>
</table>

Child-Rearing and Discipline

A change in thoughts of child-rearing and discipline had no relation to the child's health rating (lambda = 0). Eight mothers (42%) admitted a change in their ideas of child-rearing and discipline. One considered:

This is not exactly child-rearing, but we probably would have had more kids if she hadn't been sick [money, time]. Many times, especially since this
runs in families, there is a good possibility that the other child would have had asthma too.

Another couple had decided "no more" because their child was sick, but later conceived accidentally.

Four mothers (21%) indicated that discipline was less severe for the sick child.

I was more strict and I expected more out of his brother. I was easier on him. But now that he is not sick all the time I expect more from him -- it's like a cycle.

Another group of four mothers (21%) agreed, "It's harder to discipline him when he's sick, but I still think it's necessary." Two mothers (11%) had specifically been counseled by their doctor to maintain discipline. One mother had increased discipline: "I have to be more strict with them. I have to tell them not to go outside or be wrestling or jumping."

Child's Behavior Toward Mother

The child's health was strongly related to change in his behavior toward the mother (lambda = .69). Twelve mothers (63%) believed their children's behavior toward them was a result of the illness.

Five children (26%) were judged "closer" to their mothers, while another had outgrown this stage. One mother explained, "She's closer to me, constantly with me. It's like there is an invisible wire between us." A closer relationship was not always viewed as benign.
Seven children (37%) were seen as more "dependent" or demanding.

We give her a lot of attention. She is spoiled. She knows she is sick. Sometimes she cries on purpose to get sick. She doesn't want anyone else to be sick.

Two mothers described a paradoxical situation of "a more dependent child, but . . . more outgoing. She's not shy because of her contact with so many doctors and nurses."

And another mother reported, "Sometimes he has become angry at me--because I take him to the doctor for shots and to the hospital and he has to stay there."

Supervision

All mothers felt that illness had introduced some change in their supervision of the child. Seventeen mothers (90%) currently exercised some increase in supervision, as seen in Table 11. Mothers tended to keep their children indoors during certain weather conditions: wind, cold, damp, heat, and change of weather. One of the mothers who limited the amount of vigorous play said, "I'm always after her--'don't run so much!'" Mothers who restricted the child's contact with outdoor allergens were specifically concerned about bermuda grass, pollen, or loose dirt. Four mothers now, and one previously, were careful not to expose their child to others with infections. "I call to see if someone is sick if he is going somewhere." The mother who
Table 11. Current Increase in Mother's Supervision of Child's Activity\(^a\) (N=19)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weather conditions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>wind = 9</td>
<td>11</td>
<td>58.0</td>
</tr>
<tr>
<td>cold = 6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>damp = 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>heat = 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>change = 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of exertion</td>
<td>8</td>
<td>42.1</td>
</tr>
<tr>
<td>Outdoor allergies</td>
<td>7</td>
<td>36.8</td>
</tr>
<tr>
<td>Others' infections</td>
<td>4</td>
<td>21.1</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>5.3</td>
</tr>
</tbody>
</table>

\(^a\)Subjects could choose more than one option.

cared for the child with a trach was alert to the hazards of bugs, flies, and water.

Caretakers

Eleven mothers (58%) currently felt that the child's illness influenced their thoughts about others caring for him. Another two (11%) had been influenced in the past, when the child was sicker. Ten mothers (53%) were more selective because they agreed, "I would worry about it if I left them with someone. They wouldn't know what to do. And [the sick child] can get sick from one minute to the next." After experiences of diet or medicine error, the following statement mirrored the concern of many. "Other people don't
know what to do. We don't trust anyone to take care of him. We don't like to leave him any period of time." The mother with the trached child was willing to teach the caretaker, but found people were reluctant to assume the responsibility. Two mothers (11%) found that their closer relationship with the sick child influenced their thoughts about others caring for him. "He's so attached to me he can induce an attack. If others cared for him, he could get an attack."

Summary

When asked to identify the most difficult aspect of change in the mother-sick child relationship, seven mothers could think of no aspect—"It's much easier now." However, aspects of the treatment program accounted for the most difficult change in six cases. "He cried and fought. He resented me making him take his medicine." Five mothers (26%) mentioned aspects of the child's overdependence—"Getting her to let go of me a little bit. She tries to fix it so that there's no time or room for anyone else." One mother found "worry" as the most difficult aspect of change for her and the sick child. A noticeable association was seen between reports of the child becoming more dependent and dependency as the most difficult aspect of change in the mother-sick child relationship (Yule's Q = .46).

Changes in the mother-sick child relationship were regarded as the least difficult aspect of the interview
(mean = .82, range = 0 to 2.13). As seen in Table 12, there were no important relationships between difficulty scores for mother-sick child relationship and mother's age, length of illness, number of doctor and clinic visits in the last six months, and difficulty scores for the treatment program as a whole. However, r for difficulty scores of mother-sick child relationship and child's age was -.48, significant at a .05 level. Thus, 23% of the variance of mother-sick child difficulty scores can be explained by the child's age alone. The older the child, the less difficult the treatment program was likely to be.

<table>
<thead>
<tr>
<th></th>
<th>Difficulty Score for Changes in Mother-Sick Child Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's age</td>
<td>-.48*</td>
</tr>
<tr>
<td>Length of illness</td>
<td>-.22</td>
</tr>
<tr>
<td>Number of doctor/clinic visits in last 6 months</td>
<td>-.19</td>
</tr>
<tr>
<td>Difficulty score for treatment program as a whole</td>
<td>-.17</td>
</tr>
<tr>
<td>Mother's age</td>
<td>-.14</td>
</tr>
</tbody>
</table>

*Significant at .05 level.
Mother-Sibling Relationship

The patient's illness might evoke such reactions in his siblings as fear, jealousy, or anger. At the same time, the mother might have less time or energy to meet the sibling's needs. On the average, there were 1.5 children in the home plus the patient (range 0-4). The siblings' health ratings were high. In all cases, the siblings' health was rated as good as, or better than, that of the patient.

Time Spent with Siblings

Five mothers (26%) noticed a decrease in the time spent with the siblings, and an additional two (11%) had in the past. Two mothers (11%) said that they tried to compensate when the patient was well or resting. Non-symmetrical lambda for the association between the siblings' health rating and change in the amount of time the mother spends with the sibling was .40. This indicates that knowledge of the sibling's health eliminated 40% of the error in predicting change in the amount of time spent with the siblings.

Sibling's Behavior

Most mothers (79% of 14) noticed a change in the sibling's behavior toward them that might be due to the illness, as seen in Table 13. There was a mild association between the patient's health rating and change in the sibling's behavior (lambda = .42). A greater association.
Table 13. Selected Changes in Sibling's Behavior to Mother\(^a\) (N=14)

<table>
<thead>
<tr>
<th>Change in Sibling's Behavior</th>
<th>Number</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demanding behavior</td>
<td>7</td>
<td>50.0</td>
</tr>
<tr>
<td>Other emotional reaction</td>
<td>5</td>
<td>35.7</td>
</tr>
<tr>
<td>Sick role</td>
<td>3</td>
<td>21.4</td>
</tr>
<tr>
<td>Assist mother--protective to patient</td>
<td>3</td>
<td>21.4</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>14.3</td>
</tr>
</tbody>
</table>

\(^a\)Subjects could choose more than one option.

There existed between decline in time spent with the siblings and change in sibling's behavior (Yule's \(Q = .68\)).

There was a strong association between a decline in time spent with the sibling and the sibling becoming more demanding (Yule's \(Q = .78\)). Seven mothers described demanding or attention-getting behaviors by the siblings in order to divert the mother's attention from the sick child. One mother said, "When they're sick, really having problems, she becomes ornery to get the attention." In three families (21%), siblings also tried to assume sick roles. "Sometimes she might say, 'Momma, I need some medicine.'" In one case, as sibling actually developed asthma. "That's when [sibling] got sick. It was something. He is a sympathetic wheezer. He'd say, 'I'm so sick!'" In contrast, none of
the other five asthmatic siblings in the study became ill in conjunction with the patient.

Three mothers (16%) noticed protective behavior toward the sick child, but a mother of a very disturbed family said: "They resent us. They resent him. My girl feels tied down and doesn't appreciate doing anything for him."

Other emotional reactions in siblings were possible for four other families (21%). "My six year old was sort of shoved in the corner. . . . She feels this. She is a little insecure."

Information

Six of the mothers (43%) had made a specific effort to discuss the illness with the sibling. This was important for two families because the siblings had been frightened during the patient's hospitalization.

We've explained everything to them because they were so upset when [patient] was in the hospital. They thought that if she went into the hospital she wouldn't come home.

Four mothers (29%) had felt that specific information was not necessary as the sibling "... just knows everything. She's grown up with it." Three mothers (21%) had other responses: "The oldest will tell me when she gets sick," "They realize when he's having an attack, everything stops," and "... just what he asked." One mother (7%) said the sibling was told nothing. The patient's health rating had
virtually no association with the mother's deliberate efforts to inform the sibling (lambda = .09). There was a noticeable association between a change in the sibling's behavior and the mother's deliberate efforts to inform the sibling (Yule's Q = .46), and a moderate association between mother's deliberate efforts to inform the sibling and the sibling's demanding behavior (Yule's Q = .60).

Summary

A majority of the mothers identified a most difficult aspect of change for the mother-sibling relationship, but five mothers (36%) could not. Four mothers (29%) cited examples of trying to meet each child's needs or "trying to do everything for them all at the same time." This response was moderately associated with sibling's demanding behavior (Yule's Q = .64). Three mothers (21%) found enlisting the sibling's help or cooperation with the sick child's care the most difficult.

Sometimes when [patient] is sick, I'll ask [sibling] to stay in, in good weather. I feel bad, yet it's so much easier. She'll play indoors with [patient].

One mother answered, "Their acceptance. We have to watch them closer." Another discussed "... conflict. I miss out on phases, periods of my other children that I want to share."

The mean difficulty score for changes in mother-sibling relationship was 1.38. Student's t's calculated for
groups of change/no change in amount of time spent with sibling, change/no change in sibling's behavior toward mother, and sex revealed no significant differences between these groups.

Table 14 shows Pearson's $r$ for sibling difficulty scores and selected variables. Correlations for mother's age, length of illness, number of doctor and clinic visits in the last six months, and age of siblings were not statistically significant. However, knowledge of the patient's age allowed prediction of difficulty scores in 46% of families, and a number of siblings in the home prediction in 35% of families.

Table 14. Pearson's $r$ for Mother-Sibling Difficulty Score and Selected Variables (N=13)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$r$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's age</td>
<td>-.68*</td>
</tr>
<tr>
<td>Number of siblings in home</td>
<td>-.59*</td>
</tr>
<tr>
<td>Age of siblings in home</td>
<td>.41</td>
</tr>
<tr>
<td>Mother's age</td>
<td>-.28</td>
</tr>
<tr>
<td>Length of illness</td>
<td>-.05</td>
</tr>
<tr>
<td>Number of doctor/clinic visits in last 6 months</td>
<td>.03</td>
</tr>
</tbody>
</table>

*Significant at .05 level.
Mother-Father Relationship

As the mother assumes the burden of responsibility for the child's health, opportunities for strengthening or weakening her relationship with the father figure occur. All but three of the mothers interviewed (84%) were living with a spouse or father figure. Two of the women were single. The third was divorced; she attributed the break-up to disagreements when a school age sibling was ill with asthma. In these three cases the maternal grandfather was the father figure. One marriage appeared grossly disturbed. This mother said, "We just don't get along. [Patient] isn't the cause of the problem."

Activities

No relationship was seen between the child's health and change in parent activities (lambda = .08). Twelve (75%) of the couples had experienced a change in their activities together as a result of the child's illness. Nine (56%) couples' activities were currently limited. The change in parent activities was directly related to the substitute caretaker problem in all families but one, in which the mother reported the cause was "just of time."

The greatest change appeared to be in a decline in activities of the husband and wife together. Activities planned for the whole family were more frequent, although these events were also subject to the limitations imposed by
the child's illness. Four mothers (25%) found parent activities limited only when they remained home to care for an acutely ill child. Half (n = 8, 50%) were unable or unwilling to leave the child in another's care, a situation of "we just don't go or we take them [with]." Four families (25%) had virtually no one else to care for the child. The mother of the child with a trach could not find persons willing to assume responsibility for his care. As a result, she said: "We don't get a chance to do anything anymore. It's kind of depressing. We can't go out for a cup of coffee or dinner."

Relationship

No association was seen between child's health and change in parent relationship (lambda = .07). Seven of eighteen mothers (39%) felt that the child's illness had no effect on the relationship with the father figure. Six (33%) felt that the illness had resulted in a "closer" relationship. Three (17%) described both positive and negative effects of the illness. Six mothers (33%) altogether felt that the illness had caused a strain. One woman explained, "I expected more from him than he was giving." Another said, "He considered that I was hyper in my reaction to the asthma... We didn't agree on how to handle things." Five women (28%) described situations where spouse neglect was perceived by the husband.
Discussion

On a scale of 0 = not free and 4.0 = extremely free, the mean score for freedom to fully discuss the child's illness with the father figure was 3.74. Overwhelmingly, mothers reported that they felt free to voice their concerns. However, the result of this discussion was sometimes ambiguous.

As seen in Table 15, no important relationship was found between freedom to discuss the illness and child's age, length of illness, number of doctor and clinic visits in the last six months, or difficulty score of the treatment program as a whole. However, r for freedom to discuss and mother's age was -.91. Thus younger women had greater freedom to discuss the child's illness with the father figure. Eighty-three per cent of the variance in freedom scores can be explained by the mother's age alone.

Summary

Seven (39%) mothers saw no difficulty of change for the mother-father relationship. Five women (28%) replied, "Just getting used to an asthmatic child, trying to curtail things." Lack of support and understanding was the biggest problem for three families: "I get angry with him. I was the one to visit [patient] in the hospital--it bothered him. I was the one doing the dirty work." "My husband feels neglected. It's a real problem." "The treatment . . .
Table 15. Pearson's r for Scores of Mother's Freedom to Discuss Illness and Difficulty Scores for Mother-Father Relationship and Selected Variables

<table>
<thead>
<tr>
<th></th>
<th>Freedom to Discuss Illness with Father (N=18)</th>
<th>Difficulty Score for Mother-Father Relationship (N=13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's age</td>
<td>-.25</td>
<td>-.26</td>
</tr>
<tr>
<td>Mother's age</td>
<td>-.91*</td>
<td>-.41</td>
</tr>
<tr>
<td>Length of illness</td>
<td>.02</td>
<td>-.19</td>
</tr>
<tr>
<td>Number of doctor/clinic visits in 6 months</td>
<td>.03</td>
<td>.4</td>
</tr>
<tr>
<td>Difficulty for the program as a whole</td>
<td>-.02</td>
<td>.46**</td>
</tr>
</tbody>
</table>

*Significant at .05 level.
**Significant at .10 level.

hard for him to accept." The sick child sleeping with the parents was the most difficult aspect for two families. Money was the hardest aspect for one family.

The mean difficulty score for change in the mother-father relationship was 1.30. Student's t scores show no difference in difficulty scores of mother-father relationship whether or not the illness had resulted in changes of parent activities or relationships. Table 15 shows no important relationship between mother-father difficulty scores and child's age, mother's age, length of illness, or number of doctor and clinic visits. The correlation of .46 for parent difficulty scores and treatment program difficulty scores is substantively significant. Thus, 21% of
the variance in mother–father difficulty scores can be explained by treatment program difficulty alone.
CHAPTER 5

INTERPRETATION OF THE FINDINGS

This study explored the mother's view of selected changes in her family activities and relationships after a preschool child had been diagnosed with a chronic respiratory disease. This chapter will analyze the research findings in terms of the conceptual framework, review of the literature, nursing implications, and recommendations.

The Child's Illness

The cause of the child's illness had impact in two ways. First of all, the familial aspect of asthma seemed more significant than review of the literature suggested. Emphatic statements of "there's a whole history of asthma and allergies in my husband's family" indicated that blame or guilt could be associated with familial incidence. Presence of atopic relatives led to either extra sympathy and rapport or disagreement over the treatment program. Additional atopic children increased the mother's burden (London, 1970). One mother, who regularly checked the asthmatic child at night, found her sleep also disturbed by the crying of a sibling with severe excema. As a result, she concluded: "Two years ago I didn't sleep ten nights."
Another couple stopped having children due to the familial occurrence of asthma.

Secondly, the mother's care was sometimes labeled the cause for the child's illness. A mother said that after her child's first asthma attack, "... the doctor told me never to let him get that sick again or he might die." Another said of her mother-in-law: "She was sure it [the asthma] was something I was doing wrong. I wasn't bundling her up enough; I shouldn't give her water right out of the tap because it was too cold and caused asthma."

Mothers' descriptions of the early phases of the illness affirmed Hill's (1958) theories of the family's roller coaster response to stress. Nearly all families experience a crisis at some time. Family members reacted with grief and mourning (Lindemann, 1944). This information was convincing of the need for crisis intervention. The mother especially needed support until she felt confident of her skill in dealing with the sick child.

Steinhauer et al. (1974) suggested that availability of an effective treatment was a factor in family response to illness. Mothers' statements indicated that this was indeed the case; unavailability of effective treatment certainly added to the crisis situation. Three families had moved to Arizona in search of proper treatment and environment. Two of these mothers insisted on this move although it caused severe strain with the father. One couple
had taken their child to medical centers and specialists in three states without a change in the child's condition. Three mothers told of early treatment under a physician who "didn't know what to do." One girl was cared for by two doctors with conflicting opinions; the mother "got caught in the middle." A mother of a sixteen year old and a three year old with asthma felt that the oldest was still suffering from the effects of inadequate medical treatment at diagnosis. "We were young and didn't have any money, so he did not have the quality of medical care."

All but two mothers seemed satisfied with the child's current treatment. Some families were so dependent upon this care that they severely limited their activities to be nearby. One mother said, "I'm afraid to leave town with him." Another felt, "We cannot be far from the hospital. It is the only hospital that can take care of her." This family did not even travel to relatives living an hour and a half away.

The Treatment Program

The data overwhelmingly established the concept of the mother as the person responsible for the burden of the treatment program. Higher difficulty scores were associated with a shorter duration of illness ($r = .39$), indicating that the treatment program seemed less difficult with time.
Habituation seemed the key to long term adjustment to the child's illness. Activities were changed to fit the new situation, and mothers began to regard the new patterns as "normal." A mother confided, "Six months ago, [the treatment program] was extremely difficult. You have to adjust." Typical responses to the difficulty of treatment program scales were "it just becomes routine . . . natural," "I'm so used to it, it's just a set pattern," and "... [little difficulty] because I'm used to it."

Scheduling of treatments and medicines to fit in with regular family routines, cleaning and maintenance of equipment, and actual time regularly spent on medicines and treatments were not problems for most mothers. Scheduling difficulty was an important factor when determining treatment program difficulty (r = .60). Actual time regularly spent on medicines and treatments was less significant when it was learned that mothers maintained an almost constant vigilance over the child's health.

Nor was diet a problem for mothers or patients. Food allergies had already been identified. Contrary to reports in the literature, the allergic child in this sample was not tempted to eat forbidden foods. Mothers did not seem to mind denying the allergic child milk.

Medication accounted for many of the treatment problems. Medication side effects had the greatest difficulty score in the interview, and the association between side
effect and treatment program difficulty was very strong \((r = .93)\). Allergy shots were also associated with particular problems for both patients and mothers. This indicates that close communication between mother, nurse, and doctor about medication is desirable.

Time and distance made doctor visits a problem for this group of local mothers. One can only speculate as to the difficulties of families living relatively far from a medical center and/or effective treatment. Reliance must be made upon parent teaching and telephone contact.

**Mother's Daily Activities**

Changes in the mother's daily activities were rated as the second most difficult in the interview. It seemed that the demands of the child's illness and treatment often resulted in role conflict for the mother. The mother's prominent role was that of guardian of the child's health. During conflict, she was less likely to maintain other role behaviors— that of working woman, adult with outside interests, wife, individual with normal physiological needs. Most of the changes in her activities stemmed from the mother's constant vigilance over the child's health.

After diagnosis, more of her energies were spent on housework. As one mother said, "I'm more aware of the need to clean, and I have less time to do so." There was no relationship between the mother's view of the child's health
status and her current employment. However, mothers' and fathers' employment could easily have been affected by the slow economy.

The mother's view of illness influencing her choice to work emerged as a key to the family's level of reorganization. Mothers who felt the illness would influence their choice to work were more likely to view the child as sicker and the changes in her daily activities as more difficult.

Most mothers experienced a reduction in outside activities. Whole family outside activities were limited for fear of the child's exposure to allergens, infection, or inclement weather. The illness also limited time, energy, and money for outside activities. Caretaker problems resulted in even fewer adult outside activities. Most mothers were reluctant to leave the child in another's care.

The biggest change in the mother's daily activities was a disruption in her patterns of sleep. All mothers reported this change. Sleep deprivation could leave the mother with fewer resources for family activities and relationships. It was striking that fathers rarely were disturbed at night. This suggests many hypotheses, including the one that parents felt the father's role performances were more important and/or demanding than the mother's. The nocturnal occurrence of the attacks, with the mother and child spending hours alone together while others slept,
probably strengthened the bond between the two and a sense of isolation from others.

Mother-Sick Child Relationship

The child's illness was seen to modify many facets of the mother-child relationship. Generally, a pattern of protection and dependence emerged.

The mother's response to the child's illness corresponded closely to Hill's (1958) description of total family response to a stressor event. First there was shock, then a trial-and-error period in which the mother gained confidence in her skills in maintaining the child's health. Finally, the mother had developed a system of behaviors to meet the chronicity of the child's illness.

All mothers had increased their supervision of the sick child. While a certain amount of this was probably reasonable, negative sequelae were possible. Most restrictions concerned outdoor and/or vigorous play, setting the child apart as "different" from others. Accordingly, he may resent the mother's supervision. Or the child may become too comfortable in this dependent role; mothers of school age siblings expressed frustration that the older child did not "take responsibility for his asthma."

Mothers were reluctant to relinquish the child's care to others. Their comments indicated a sense of distrust and alienation of the outside world ("they wouldn't
know what to do") that could lead to a degree of social isolation.

The illness and treatment program seemed to bind mother and sick child closer together. Each was more likely to seek gratification with the other. Mothers found positive aspects of change in their relationship with the sick child, suggested by the lowest difficulty score in the interview.

Almost half of the mothers found it harder to discipline the sick child. Perhaps this supports the theory found in the review of the literature that overprotective mothers have difficulties setting limits.

There was a strong negative association between the mother's view of the child's health and a change in the child's behavior toward the mother. The sicker children were more likely to become closer to or more dependent upon the mother. This could be in response to the illness and treatment itself, or to changes in the mothers' feelings and behaviors. There seemed to be an overlap between mothers' terms of "closer" and "dependent." The women seemed to have ambivalent attitudes about the closer relationship and the child's increased dependence.

School appeared to loosen the ties of overprotection and dependence. Children in the study only spent a few hours a day at Head Start programs for kindergarten, yet the child assumed a new and more independent role. Some
mothers' comments were: "I worried how she'd do at that school, but she seems OK," "Now that he is in school he's doing very well. He doesn't pay as much attention to his nose running, and so forth," "She'll be going to school next year and we'll have to break apart."

The correlation between difficulty scores in mother-sick child relationship and child's age was -.48, meaning that changes were more difficult when the patient was younger. This could be due to the shorter bond between mother and child or growth and development factors. Again, the child's school experience could be significant.

**Mother-Sibling Relationship**

Family size and structure, relationships within the family, and the patient's role in the family were all variables affecting change in the mother-sibling relationship after the diagnosis of a chronic respiratory disease in the patient. Change in the mother-sibling relationship seemed to vary according to the well child's perception of the illness as a threat.

When the illness decreased the amount of time spent with the sibling, he was likely to react with demanding or attention-getting behavior (lambda = .78). Difficulty scores for changes in sibling-mother relationship declined with the number of siblings, perhaps because children in larger families were not so dependent upon having their
needs met by the mother. The correlation for difficulty scores and patient's age was \(-0.68\), indicating strain between mother and siblings was the greatest when the baby of the family was ill.

Turk (1964) had found a "web of silence" in cystic fibrosis families. To a certain extent, this was also true in study families. Only six mothers indicated they made a specific effort to discuss the illness with the sibling at least once. Most communication about the illness seemed non-verbal. As reported by the mother, siblings picked up on the emotional climate during attacks, the mother's changed behavior toward the sick child, and the decrease in mother's time with themselves.

Although mothers assumed the siblings would know about the illness from years of living with it, it would be interesting to learn actually what the well child's perceptions were. Certainly distortions and misconceptions could occur even in older siblings, which would need to be clarified. Magical thinking of young children would affect perceptions even more. A nursing priority should be to discover the sibling's views of the sick child, illness, and effects of the illness on family activities and relationships. Family counseling may open verbal communication about the illness and its results.
Mother-Father Relationships

After the child had been diagnosed with a chronic respiratory disease, the mother became the guardian of the child's health. Her family activities and relationships changed as she assumed the burdens of the treatment program. The quality of the evolving mother-father relationship was dependent upon role agreement and support.

Mothers tended to take the illness seriously, enter a more intense relationship with the sick child, and give the treatment program priority over other activities. They expected the father figure to live in an environment suitable to the patient's health, accept the child's condition, support the family if possible, and generally assume an operational role.

To the extent that the mother was willing to assume her role, and the father accepted the situation, the mother-father relationship was a positive one. The parents felt they made a satisfactory adjustment to the changes of the illness. When the father gave the mother emotional support, the coping mechanism of detouring (Minuchin et al., 1975) occurred; mothers were likely to say the illness brought them closer together. If the father simply accepted the situation, neither supporting or criticizing, the mother tended to say the relationship was unchanged or closer.

Sometimes the parent dyad was split. The father's disagreement over the treatment plan, denial of the child's
illness, rejection of the mother's role, or perceived neglect by the wife all led to strains in the mother-father relationship. Either triangulation or parent-child coalition resulted. In only one case, the sick child was allied with the father. "My husband won't let me hit him, and he knows it." In all other cases of parent-child coalition, the mother and sick child formed a coalition against the father. The father could react either passively or protest.

Activities of the husband and wife alone together declined. That, together with the decrease in the mother's other adult outside activities, suggests that mothers were deprived of adult recreation.

The amount of knowledge generated from the question "How free do you feel to fully discuss the illness and its problems with the father?" was disappointing. The mother's feeling free to discuss the illness did not mean topics were necessarily resolved. Perhaps the question regarding parent communication should ask about parental agreement on aspects of the treatment program, or identify which topics were very easy or very hard to discuss honestly. The very strong negative association between mother's age and freedom to discuss (r = -.91) was interesting, but mothers' comments did not reveal why this should be the case. One can only hypothesize that the younger woman's cultural background was either more supportive of open discussions and sense of partnership with the spouse, or a need to convince the
interviewer that this was the case. An alternate hypothesis is that mother's freedom to discuss the illness was associated with the number of years married.

Treatment program difficulty and difficulty of parent changes rose together, allowing prediction in at least 21% of cases. The interview schedule elicited only minimal information on parent response to the child's illness. A more complete investigation of this area is strongly urged.

Conclusion

This chapter has dealt with generalization and conclusions from the data, as well as nursing implications. Potential categories identified in the data might be useful in the development of a family assessment tool. The final chapter will present a summary of the study.
CHAPTER 6

SUMMARY

This chapter is a summary of the study exploring the mother's view of selected changes in her family activities and relationships after a preschool child has been diagnosed with a chronic respiratory disease. The purpose of the research, methodology, findings, conclusions, and recommendations are discussed.

Purpose of the Research

Chronic illness affects a patient and family in a variety of ways. This study focused on one vital family member, the mother, and her views of selected changes in her family activities and relationships after the child had been diagnosed with a chronic respiratory disease. Mothers described these changes, and rated the difficulties they presented. The information gained could guide development of a family assessment tool.

Methodology

An exploratory design was used in this study. An interview schedule was developed with the following topics: general information, the treatment program, the mother's daily activities, mother-sick child relationship,
mother-sibling relationships, mother-father relationship. This schedule guided a semi-structured interview with nineteen mothers of preschoolers which chronic respiratory disease. These subjects had been contacted from lists of possible families supplied by pulmonary clinic staff. Categories of response were developed from the data, and frequencies and correlations calculated.

**Research Findings**

Most mothers described at least one crisis situation at some stage of the child's illness. By the time of the interview long term adjustments in family activities and relationships had been made. Asthma was at least suspected in all children but one; many had allergies. The illness was episodic. Treatment included antihistamines, decongestants, vaporizers, aerosol treatments, and percussion and drainage. Side effects of medicines presented real problems for mother and child. The most frequent side effects were hyperactivity and nausea and vomiting. Allergy shots were thought to improve the child's health, but were associated with child protest of shots and mothers disliking doctor visits. Actual time regularly spent on medicines and treatments was low, but mothers maintained an almost constant vigilance over the children's health.

The illness was seen to change many of the mother's daily activities. A mother who felt the illness would
influence her choice to work was more likely to view the patient as sicker and changes in her daily activities as more difficult. Mothers of allergic children experienced a considerable increase in their housework. Outside activities were limited by the sick child's susceptibilities and caretaking needs. All mothers experienced disruption in their patterns of sleep. The mother usually stayed up with the sick child during nocturnal attacks.

Almost half of the mothers felt the illness had influenced thoughts of childbearing and discipline. A similar number found it harder to discipline the sick child. Patients became closer to the mother or exhibited demanding or dependent behavior. Nearly all mothers increased their supervision of the child's activities, usually limiting outdoor or vigorous play. Most mothers felt the illness had changed their thoughts of others caring for the child, because others did not know how to care for the child or the child would cry himself into an attack. Changes in the mother-sick child relationship were rated as the least difficult in the interview. Higher difficulty scores were associated with younger patients.

There were an average of 1.5 siblings in the home with the patient. Most mothers noticed a change in the sibling's behavior toward them that might be due to the child's illness. There was a strong association between decline in time spent with the sibling and the sibling
becoming more demanding. Only six mothers indicated that they made a specific effort to discuss the illness with the sibling. However, siblings were thought to absorb non-verbal communication about the illness, noticing changes in emotional climate and the mother's behavior. Greater difficulty scores for changes in mother-sibling relationship were associated with younger patients and fewer siblings.

Seventy-five per cent of couples experienced a decrease in activities. The greatest change was in activities of the mother and father alone together. This problem was related to the babysitting situation. Forty per cent of mothers felt the illness had not changed their parent relationship. The stress of the illness had potential for a closer relationship or strain. A substantively significant association was seen between difficulty of treatment program as a whole and difficulty of parent relationship.

Nearly all reported changes in the mother's family activities and relationships stemmed from her constant vigilance over the child's health. Her role of guardian of the child's health superseded others.

**Recommendations**

The interview schedule could be improved by substituting other questions for frequency of mother and sick child sleeping in the same room and mother's freedom to discuss the illness fully with the father. These questions
did not seem to probe significant areas of change effectively. It seemed that a more sensitive scale for difficulty of changes would be useful. Sections on the mother-sibling relationship and the mother-father relationship could benefit from expansion. It is recommended that a modified interview schedule be used to replicate the study in another setting, with mothers of school age children, or with mothers of children with different chronic illnesses. It is especially hoped that a family assessment tool be developed to study further response to illness and health care. Formulations of alternative research methodologies (i.e., observation in the home, second interviews, longitudinal studies, etc.) and development of concepts for further research in the patient's view and patient's participation in health care are also recommended.
**APPENDIX A**

**INTERVIEW SCHEDULE AND SELECTED RESPONSES**

A. **GENERAL INFORMATION**

1. **Date**

2. **Patient**

<table>
<thead>
<tr>
<th>N=19</th>
<th>Sex</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>13</td>
<td></td>
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</table>

3. **Age**

<table>
<thead>
<tr>
<th>Mean</th>
<th>Range</th>
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<tbody>
<tr>
<td>43.7 mos</td>
<td>15 to 60 mos</td>
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4. **Gender**

<table>
<thead>
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<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6</td>
<td>13</td>
</tr>
</tbody>
</table>

5. **Siblings**

<table>
<thead>
<tr>
<th>No. at home</th>
<th>Sex</th>
<th>Age</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>n = 5</td>
<td>mean 8.2 yr</td>
<td>Exc n = 13</td>
</tr>
<tr>
<td>1</td>
<td>n = 5</td>
<td>range = 1 mo to 17 yr</td>
<td>good n = 10</td>
</tr>
<tr>
<td>2</td>
<td>n = 5</td>
<td></td>
<td>fair n = 6</td>
</tr>
<tr>
<td>3</td>
<td>n = 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>n = 2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. **Other members of the household**

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Sex</th>
<th>Age</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>mother</td>
<td>n = 1</td>
<td>mean 32.2 yr</td>
<td>Exc = 3; good = 9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>range 25-26 yr</td>
<td>(mode); fair = 6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>poor = 1</td>
</tr>
<tr>
<td>father</td>
<td>n = 2</td>
<td>mean 37.2 yr</td>
<td>Exc = 2; good = 11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>range 27-63 yr</td>
<td>(mode); fair = 3</td>
</tr>
</tbody>
</table>

7. **Child's diagnosis**

   asthma = 14 (mode); "probably" asthma = 4

8. **Child's age at time of diagnosis**

   mean 21.9 mo, range 0-60 mo

9. **Child's age when symptoms began**

   mean 14.0 mo, range 0-42 mo

10. **In the last 6 months, how often has ___ visited the doctor or clinic?**

    mean = 10.7, range 0-33

11. **In the last 6 months, how often has ___ visited the ER?**

    mean = 1.0, range 0-5

12. **How would you describe ___'s health?**

    excellent = 1, good = 11, fair = 4, poor = 2, very poor = 6 (mode)
B. TREATMENT PROGRAM

1. What kinds of medicine, if any, does ___ receive?
   mean = 2.8, range 0-6
   replacement enzymes ___ antibiotics ___ vitamins ___
   cortisone ___ aminophyllin ___ other dilators and anti-
   histamines

2. What kinds of treatment, if any, does ___ receive?
   P and D n=5 IPPB ___ breathing exercises ___
   aerosols n=4 vaporizer n=7 other suction = 1, none = 7

3. What kind of diet is ___ on?
   Regular n = 9 minor restrictions (chocolate etc.) n = 2
   milk free n = 6; isomil n = 2; multiple restrictions n = 2

4. The next question relates to scheduling medicine and treatments to fit in with regular family routines.
   Please circle the spot on the card which best describes this situation. (Stem question--"I find scheduling medicines and treatments to fit in with regular family routines . . . ")

   (Scale on 3 x 5 card presented to mother will appear:
   0 1 2 3 4 mean = 1.06 range 0-3.06
   not extremely difficult difficult
   n = 19

5. Is any cleaning or maintenance of equipment necessary?
   yes = 9; no = 10
   If yes, who does this? mother n = 19
   How much time does this take per day? few minutes

6. Who supervises the treatments and medicine? mother

7. How much time do you spend per day on treatments and medicine?

8. Have you noticed any side effects of medication?
   yes = 13 (including 4 in past); no = 6
   If yes, please mark the spot on the card which best describes these side effects.
9. Is there any aspect of the treatment program that ____ protests or resists?
   If yes, which aspect(s)?
10. Is there any aspect of the treatment program that you dislike giving?
   If yes, which aspect(s)?
11. Some parts of the treatment program might be more difficult than others. Which aspect of the treatment program is the most difficult?
12. This question concerns the overall nature of the treatment program. Please choose the point on the card which best describes the treatment program as a whole.

   (Scale on 3 x 5 card presented to mother will appear:)
   0 1 2 3 4 mean 2.29
   not extremely difficult
difficult

   range .50 - 4.06
   n = 9

C. Now let's talk about some of your usual activities?
1. Before ____ became ill, were you employed? yes = 10
   Are you now employed? yes = 10; no = 9
   per cent agrmt--before/now 57.9%; no/yes 3; yes/no 5
2. Do you think ____'s illness would have any influence on your choice to work? yes = 8; in past = 2; no = 9
   If yes, how?
3. As a result of ____'s illness, has there been a change in your housework?
   If yes, decrease n = 13 increase n = 9 no change = 7
4. As a result of ____'s illness, has there been a change in your activities outside the home? 
   yes = 16
   no = 3

   If yes, what changes have occurred?

5. As a result of ____'s illness, has there been any change in your sleeping patterns? 
   yes = 19

   If yes, what are these changes?

   If not answered above, has there been any disruption of the mother's sleep?

   If yes, how often?

6. This question asks how often you sleep in the same room as ____. Please choose the answer on the card which describes how often this occurs.

   (Scale on 3 x 5 card presented to mother will appear:)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>mean = .80</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range 0-4.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n = 19</td>
<td></td>
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</tbody>
</table>

7. Some aspects of change in your usual activities might be more difficult than others. Which aspect of change in your daily activities has been the most difficult?

8. This question refers to the changes that have occurred in your usual activities. Please choose the point on the card which best describes these changes.

   (Scale on 3 x 5 card presented to mother will appear:)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<tbody>
<tr>
<td>not difficult</td>
<td>extremely difficult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean = 1.45</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range 0-4.06</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>n = 19</td>
<td></td>
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</table>

D. Now let's talk about you and ____.

1. As a result of ____'s illness, has there been any change in your thoughts of child-rearing, and discipline? 
   yes = 7; past = 1; no = 11

   If yes, what have these changes been?

   4 less discipline
   1 more discipline
   4 harder to discipline
2. Do you think there have been any changes in ___'s behavior toward you as a result of his illness?  
   yes = 12; no = 7
   If yes, what are these changes?

3. As a result of ___'s illness, has there been any change in your supervision of ___'s activities?  
   yes in past only = 2; yes now = 17
   If yes, what are these changes?
   If not answered above, has there been a change in supervision of
   place
   playmates
   kind of activity
   amount of playtime

4. Has ___'s illness influenced your thoughts about others watching or caring for ____?  
   yes = 11; past = 2; no = 6
   If yes, how?

5. Some aspects of change with you and ____ might be more difficult than others. Which aspect is the most difficult?

6. Looking at the card, which point best describes the changes between you and ____?
   (Scale on 3 x 5 card presented to mother will appear:)
   mean = .82  
   range 0-2.13
   not extremely difficult  
   n = 18

E. Now let's talk about you and your other children. n = 14

1. Has ____'s illness changed the amount of time you spend with the other children? now = 5; in the past = 2
   If yes, how?

2. Have you noticed any changes in your other children's behavior toward you that might be due to ____'s illness?  
   yes = 11; no = 2; not sure = 1
   If yes, what are these changes?
3. What, if anything, have you told the other children about ____'s illness? discussion initiated by mother = 6; "they already know" = 4; other = 3; nothing = 1

4. Some of the changes with you and the other children might be more difficult than others. What aspect of change has been the most difficult?

5. Looking at the card, which point best describes the changes that have occurred with you and the other children?

(Scale on 3 x 5 card presented to mother will appear:)

\begin{align*}
0 & \quad 1 & \quad 2 & \quad 3 & \quad 4 \\
\text{not} & \quad \text{extremely} & \quad \text{difficult} \\
\text{difficult} & \quad \text{free}
\end{align*}

mean 1.38
range 0-4.00
n = 13

F. Now let's talk about you and your husband. (If husband is not a member of the household, ask if there is someone who has taken his place for the child. If so the questions will deal with mother and this person.)

1. Have there been any changes in your activities together as a result of ____'s illness? now = 9; past = 3; none = 1

If yes, what are these changes?

2. This question is about how free you feel to discuss ____'s illness fully with (father or father figure). Looking at the card, which point best describes this situation?

(Scale on 3 x 5 card presented to mother will appear:)

\begin{align*}
0 & \quad 1 & \quad 2 & \quad 3 & \quad 4 \\
\text{not} & \quad \text{extremely} & \quad \text{free} \\
\text{free} & \quad \text{very free}
\end{align*}

mean 3.74
range .50-4.06
n = 13

3. What, if any, effect do you thing ____'s illness has had on your relationship with (father or father figure)? none = 6; closer = 6; strain = 6 negative and positive = 3

If some effect, can you tell me more about this?

(If above responses have indicated any change or effect, proceed.)
4. Some of the changes between you and (father or father figure) might be more difficult than others. Which aspect of change has been the most difficult?

Looking at the card, what point best describes the changes that have occurred for you and (father or father figure)?

(Scale on 3 x 5 card presented to mother will appear:)

<table>
<thead>
<tr>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
</tbody>
</table>

mean 1.30
range 0-3.88
n = 13
APPENDIX B

SUBJECT'S CONSENT FORM

You are being asked to participate in a study exploring what changes, if any, a child's illness presents for the mother. The information will help nurses better care for sick children and their families.

If you are willing to participate, there will be one interview session with the researcher lasting 30 to 40 minutes. The interview can take place in the clinic or in your home, whichever is more convenient for you. The interview will cover the treatment program, your daily activities, your relationship with your sick child, your relationships with your well children, and your relationship with your husband. All information will be kept confidential.

It is possible that you might experience slight discomfort during the interview session. However, if you do not wish to answer certain questions or to withdraw at any time, you will be free to do so without ill will or risk to your care.

I have read the above "Subject's Consent." The nature, demands, risks, and benefits of the project have been explained to me. I understand that I may ask questions and that I am free to withdraw from the project at any time without ill will.

Subject's Signature __________________________ Date _________

Investigator's Signature __________________________ Date _________
5555 E. 14th St.
Tucson, AZ 85711
Nov. 12, 1976

Dear ________

I am a graduate student in child nursing at The University of Arizona. I am conducting a study to explore what changes, if any, a child's illness presents for the mother. The information gathered will help nurses better care for sick children and their families.

Mothers of children seen at St. Luke's Clinic are being asked to participate in this study. Your child's doctor has given his permission to this research. Participation in this study will consist of one thirty-minute interview in your home. I will call you in a few days to explain the study further.

Sincerely,

Cheryl Cameron
<table>
<thead>
<tr>
<th>Family</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>In the morning, I have to take care of [sick child] first. My other child starts to resent this.</td>
</tr>
<tr>
<td>2</td>
<td>None. I do things in the morning, just worked around him.</td>
</tr>
<tr>
<td>3</td>
<td>She goes to nursery school and it becomes difficult to accept she is OK there.</td>
</tr>
<tr>
<td>4</td>
<td>Getting up at night. I do get up at night and then I don't get back to sleep.</td>
</tr>
<tr>
<td>5</td>
<td>His diet. I end up restricting everyone's diet and then I don't get to eat a lot of things I want.</td>
</tr>
<tr>
<td>6</td>
<td>Not being able to fulfill outside obligations.</td>
</tr>
<tr>
<td>7</td>
<td>When she was very sick, having to stay home so she wouldn't be exposed. She was very low in gamma A.</td>
</tr>
<tr>
<td>8</td>
<td>It [his illness] has changed the whole thing. I became overprotective and he has become overdependent.</td>
</tr>
<tr>
<td>9</td>
<td>Take treatments. [It's] something we have to do, don't want to.</td>
</tr>
<tr>
<td>10</td>
<td>Getting up in the middle of the night. The things we do for his asthma are just a way of life now.</td>
</tr>
<tr>
<td>11</td>
<td>Just worry. Wondering if he'll ever get well. I worry about it.</td>
</tr>
<tr>
<td>12</td>
<td>[Just that we] can't go to ballgames.</td>
</tr>
<tr>
<td>13</td>
<td>Keeping my house clean.</td>
</tr>
</tbody>
</table>
It's not really difficult. I make a concentrated effort. I always have to know what's going on all over the house. He can only stand 3 to 4 minutes of rough stuff.

If they're sick and they want you to be with them all the time. You can't get your work done.

It's hard for me to restrict them in their activities.

She wants more attention when she gets real sick.

[Especially when he first came home] arranging or organizing my daily chores. They have to be done around his schedule.

Cleaning.
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