COMMUNICATION PATTERNS
IN FAMILIES
WITH A CHRONICALLY ILL CHILD

by

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ABSTRACT

This exploratory study was designed to elicit information on how parents communicate about their child's chronic illness within the family and the guidance they have received from health professionals in communicating about the illness.

The study was conducted with a convenience sample of 13 parents from 11 families of children with cystic fibrosis. A semi-structured interview schedule was used with each family. The data collected were summarized into categories and descriptive statistics were utilized. All 11 families described difficulties in one or more areas of communicating about the illness. Only one parent had received specific guidance from health professionals on communicating about cystic fibrosis.

The results of this study suggest that most parents do not give their children sufficient information about cystic fibrosis to enable them to cope effectively with the illness. Also, parents do not discuss their own feelings about living with a chronically ill child nor do they encourage their children to talk about their feelings.

This lack of communication about the facts and feelings of living with cystic fibrosis appears to be related to two factors. One factor is that parents do not know how to
communicate about the illness and its effects on the family. They need guidance in providing children with adequate and age-appropriate information, in checking children's understanding of the illness and in encouraging children to express their feelings. The other factor is that parents do not perceive the importance to their children of having a thorough understanding of cystic fibrosis, nor the importance to them of having opportunities to express their feelings.

Further research is required to identify the knowledge, feelings, and perceptions of chronically ill children and their siblings.
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CHAPTER I

INTRODUCTION

Chronic illness in a child creates a stressful situation for the whole family. Not only does it pose major problems of adjustment for all family members (Kaplan, 1973) but it has implications for the mental health, relationships and even the continued existence of the family (Steinhauer, 1977).

Only in recent years have health professionals recognized the importance of extending support to the family of the ill child, especially the parents. Since it is the parents who are most responsible for meeting the needs of the individual members, their failure to cope with the illness may preclude sound coping by the rest of the family (Kaplan, 1973; Grossman, 1972). As Burton (1975) stresses: "The parents' reactions affect the child, colouring his approach to the disease, therapy and life in general" (P.3).

What support do parents of chronically ill children need in order to cope effectively with the illness, i.e. to master the problems associated with the stress of chronic illness (Kaplan, 1973)? Before answering that we must begin with a better understanding of how families do cope with the stress of having a chronically ill child. Adaptive and maladaptive coping patterns must be identified before health professionals
can provide the support these families need.

Several authors have identified a variety of coping tasks which face the family of the chronically ill, and which are necessary to complete if successful adaptation is to occur. (Kaplan et al., 1973; Livsey, 1972; Olsen, 1970; and Caplan, 1963). One task frequently mentioned but which has received little research attention is that of communication about the illness within the family. Tropauer et al. (1970) stress that ineffective coping results when communication is lacking, when the child is not educated about his illness and when his needs and feelings are not perceived. Burton further emphasizes the importance of communicating about the illness:

Not talking about the illness would seem to handicap the child additionally in terms of his understanding of the illness, his ability to speak of it and most important his ability to gain reassurance and emotional comfort (Burton, 1975, p.138).

Purpose of the Study

The purpose of the present study is twofold. The first purpose is to describe one area of family coping with chronic illness; that of family communication about the illness. The second purpose is to identify what guidance the parents have received or would like to receive from health professionals to assist them in communicating about the illness within
Problem Statement

This study will address the following specific questions:

How do parents communicate about their child's chronic illness within the family?

What guidance have they received or would they like to receive from health professionals on communicating about the illness?

Background to the Problem

The investigator's interest in the area of family communication about chronic illness began while she was working on a pediatric oncology ward. Several phenomena were repeatedly observed. When the child with cancer was hospitalized for prolonged periods, his mother spent most of her days and evenings at his bedside, although she often had other children at home. The father was rarely present and the siblings almost never came to visit. Despite the painful procedures which the child had to undergo, the number of re-admissions he had, the number of other sick and dying children surrounding him, mother and child never seemed to talk about the illness or their feelings about it. Yet there were frequent signs that they were worrying about it silently; a mother would leave her child's
room dry-eyed, only to be found in the washroom crying her eyes out; or, as in one instance, a ten year old child who supposedly didn't know she had cancer drew a picture of a horse drawing a cart with a casket in it.

The investigator became concerned about the possible negative effects the above factors might have on the family's functioning and the apparent lack of support these families were receiving from the health professionals who came in contact with them. Therefore, it was decided to investigate the problem by first establishing if the behaviors observed were common phenomena among families of children with a chronic, life threatening illness. Secondly, the investigator wanted to determine if the parents had received guidance from health professionals in communicating about the illness or if they perceived the need for such guidance.

Significance of the Problem

Several investigators have found that parents do have difficulty communicating about their child's chronic illness within the family. Tropauer et al. (1970) found that 9 out of 18 mothers said they had no discussion about cystic fibrosis with either the ill child or his siblings and 4 of them said they concealed the facts of the illness from the children. McCallum and Gibson (1970) found in their study that approxi-
mately one third of parents of school aged children avoided giving the child any information about his illness. Turk (1964) found significant problems in communication between family members. A significant number of parents did not discuss their child's illness with their well children and 60 percent of them never discussed the diagnosis with the sick child. Similarly, Burton (1975) found that the majority of 53 families she studied, did not communicate effectively about the illness with either their well children or the child with cystic fibrosis. Kulczycki et al. (1969) noted varying degrees of discomfort in talking about cystic fibrosis in the 20 families they studied. They also noted little or no discussion of feelings amongst family members. Cytryn et al. (1973) found similar results in the 29 families of children with cystic fibrosis they studied. Almost all parents were unable or unwilling to talk with their child about his feelings. Even factual information was reluctantly or partially communicated and only in a few cases did the child express a full understanding of his illness. In none of these cases had parents been given help in examining their own feelings or those of their child about cystic fibrosis. The latter study was the only one found which actually investigated the support families had received in communicating about the illness.
Potential Significance of the Study

It is hoped that the information elicited in this study will assist health professionals in their understanding of how families with a chronically ill child communicate about the illness within the family. It is also hoped that it will lend support to the important role that health professionals play in assisting families in their communication about the illness.

Definition of Terms

Communication - for the purpose of this study, verbal statements of feelings and facts about the illness.

Chronic illness - for the purpose of this study, cystic fibrosis.

Family - mother and/or father, ill child and siblings.

Assumptions

1. It is assumed that parents have responded truthfully to the questions.

2. It is assumed that the parents' perceptions of how they communicate are an accurate representation of what actually occurs.
3. It is assumed that families of children with cystic fibrosis have feelings about living with a chronically ill child.

Limitations

1. Due to the small size of the sample, the generalizability is limited.

2. The study describes the parents' perception of how they communicate which may or may not reflect what actually occurs.
The purpose of the literature review is to determine the present state of knowledge in the area of family communication about a child's chronic illness. The general theoretical frameworks within which this research was conducted are coping theory and communication theory. The theoretical proposition central to this line of research is that in order for a family with a chronically ill child to cope effectively, it is necessary for them to have a realistic understanding of the illness and its effects on individual members and to communicate this openly with one another.

**Coping Theory**

Coping as a broad concept includes mastery of any new situation or problem (Murphy, 1962). It is a kind of problem solving; therefore to cope effectively it is necessary to recognize and understand the problems (Wrightsman, 1979). Several authors have emphasized the importance of information seeking in the process of coping (Lazarus, 1977; Hamburg et al., 1967; Grossman, 1972; Schulman, 1976). Intellectual mastery gives a sense of control over stressful situations whereas the unknown creates anxiety (Janis, 1958; Futterman & Hoffman, 1973).

Lazarus (1966) also emphasizes the key role of cogni-
tive appraisal and, therefore, the meaning attached to stress-stimuli, in determining the type of coping pattern used by the family. The diagnosis of chronic, life-threatening illness in a child poses a threat to the family. This leads parents to cognitively appraise the threatening situation, which includes assessing the degree of the threat, determining the availability of options, the strength of personal resources and one's sense of competence to master the situation (Lazarus, 1966). Once the individuals involved have appraised the situation, they then employ certain coping processes based on their individual coping style. This coping style is influenced by such factors as early social experience, past experience with stress and success in dealing with it, and disease related factors. Whatever the coping style employed by individuals it has cognitive, affective and behavioral aspects (Kiley, 1972).

![Investigator's Schematic Representation of the Coping Process](image-url)
Lipowski (1970) identifies two general modes for dealing cognitively with the fact of illness. One is minimization in which denial, rationalization and selective inattention are operative. The other is vigilant focusing which is characterized by its obsessional nature, including sharply focused attention to detail, narrowing of interests to matters relevant to the illness, rigidity of opinion, and inflexibility in adapting to the unexpected. There is also scepticism of medical competence and quickness to criticize. Individuals who are using vigilant focusing need repeated explanations and discussions of the illness and its management and thorough explanations of all procedures. Failure to do this may increase the individual's anxiety and hostility.

Research has shown that parents employ both modes of cognitive coping in dealing with their child's chronic illness. Vigilant focusing is most commonly seen in parents when their child is very ill or dying whereas minimization is frequently seen in the first few months following the child's diagnosis. Burton (1975) found in the parents she studied that denial was the most widespread defense mechanism used in the first weeks after the child was diagnosed with cystic fibrosis. As a result parents often did not recall what was said to them at the initial conference and many gaps remained in their knowledge. Wood, Friedman & Steisel (1967) reported similar
results in their study of parents of children with phenylketonuria. They found that parents had surprisingly little accurate knowledge and some misinformation about the condition despite the fact that all were given accurate information by their physician when the child was first diagnosed.

Hamburg & Adams (1967) have been involved for over sixteen years in collaborative studies which explore the ways in which individuals cope with stressful events such as life threatening illness. They found that people go through stages similar to those identified by Kubler-Ross (1969) in the dying patient. First there is denial and avoidance of the nature of the illness which permits the individual to make a gradual transition to the experience. When individuals begin facing their illness they seek more information about factors relevant to the illness. With the reality comes periods of depression.

The authors stressed that the transition from denial to recognition of the reality of the situation was accomplished as a series of approximations through which an individual came to a gradual understanding of his situation. Grossman (1972) reported similar results in her study of siblings of retarded children. She found that many of them described a long process of gradually coming to understand and cope with the idea of a sibling's handicap. Due to the frequency of this mode of coping with chronic illness, Burton (1975) recommended that parents
visit the doctor on several occasions following the diagnosis so facts could be imparted gradually and clarified.

The affective-emotional aspect of coping is significantly influenced by the individual's cognitive coping style. (Lazarus et al., 1957; Fritz, 1957; Lazarus, Deese & Osler, 1951). The individual's personal interpretation of the illness in terms of consequences to himself or his important relationships and/or goals is responsible for his emotional response. (Kiley, 1972). Lazarus (1966) argues that an individual's expectations about his ability to deal with the stressful situations are an important factor in determining whether the person will feel threatened or challenged. To the extent that he prepares himself to function adequately in the stressful situation, he thereby changes the nature of the transaction along with the emotions he might have experienced had not anticipatory coping occurred. According to Lazarus (1966) this reverses the usual belief that coping follows emotion or is caused by it. He suggests that coping precedes emotion and influences its form and intensity. This theoretical proposition provides a rationale for preparing parents to cope with chronic illness in their child through anticipatory teaching. This would provide them with knowledge and the expectation to be able to deal with their children's behavior, questions, etc., thereby reducing the emotional reaction they might otherwise
experience.

Many investigators have examined the effect of advance preparation in helping individuals cope effectively with stressful situations. Janis (1958) found in his classic study of surgical patients that those who had prior information about post operative events fared better post operatively and had earlier discharge dates than did the control group who had no preparation. Considerable evidence exists to suggest the importance of accurate knowledge to a child's ability to cope with illness (Wolff, 1969; Kliman, 1978; Cain, 1964; Tropauer et al., 1970). Also, studies of parents of chronically ill children have shown that parents who intellectually master the situation gain a sense of control and cope more effectively than those whose knowledge is limited (Futterman & Hoffman, 1973; Stone, 1967; Felzen, 1970).

In summary, the aspect of coping theory which is pertinent to this study is that to cope effectively with stressful situations one must have accurate and complete knowledge and understanding of the situation which occurs gradually over a period of time.

Communication Theory

The major functions of communication for all living systems are adaptation to the environment and the establishment
and maintenance of relationships with others (Thoyer, 1968). If the individual is to adapt successfully to his environment and establish meaningful relationships, he must communicate effectively.

The most basic element of communication is perception, the process by which people select, organize and interpret sensory stimulation into a meaningful picture of the world (Berelsen & Steiner, 1964). In other words, it is the process of making sense out of one's experience (Haney, 1973). Obviously, what kind of sense one makes out of a situation has a great influence on how he responds to that situation. Since no two people learn the same lessons from life or have exactly the same environments, no two individuals will perceive situations exactly the same way (March & Simon, 1958).

The prime obstacle of every form of communication ... is simply the fact of difference ... the great gap is the gap in background, experience, motivation ... If we cannot close that gap we must at least acknowledge it (Fortune, Vol. 42, 1950).

Combs (1971) states that, "What is communicated is not necessarily what is intended but what is understood" (p. 250). The importance of perception in communicating with others cannot be overestimated. Studies have shown that when individuals do not check the other person's understanding of the situation, misperception and therefore, ineffective communica-
tion results. Korsch et al. (1972) found in their study of families of children undergoing hemodialysis that the priorities and value systems of the professionals were often at great variance with those of the family. For example, nephrectomy was seen as a step toward rehabilitation by professionals but it was perceived as a loss or setback to the family. The investigators reported that they learned to explore how a particular treatment or experience was perceived by the family before assuming it would be accepted on the terms on which it was offered.

Piaget (1952), in his pioneering research in children's cognitive development, has shown that children below the age of seven or eight years are especially prone to misperceptions. Cain (1964) found that children's pathological reactions to the death of a sibling were due to their distorted concepts of illness and death. Child psychiatrists have stressed the importance of exploring the child's perceptions of events that affect him so misperceptions can be uncovered and corrected to prevent disturbed reactions (Fraiberg, 1959; Wolff, 1969; Kliman, 1978). Wolff (1969) says children between two and seven years are dependent on adults to help them make sense of their illness.

Another important element of effective communication is self-disclosure, which is defined as a voluntary process of
revealing one's personal beliefs, values, feelings and perceptions to another (Jourand, 1971). Research suggests that self-disclosing individuals tend to be emotionally healthier than individuals who do not self-disclose (Jourard, 1971; Johnson, 1972). Caplan (1963) states that the two most basic tasks of effective coping are: (1) active exploration of reality and (2) acceptance and expression of all feelings both positive and negative.

McCallum (1975) emphasizes the importance of parents helping their children to learn how to talk about their feelings:

Most parents say a great deal to the young child about the world he lives in, his behavior and their attitudes towards it but few parents talk to young children about their feeling states, 'you seem sad, John', etc. When this is done it helps the child to recognize and identify his emotional experiences and gradually learn to express them in words ... effectiveness in communicating his feelings is one of the most important personal assets a child can develop (McCallum, 1975, p.74).

Other authors have emphasized the importance of parents of chronically ill children establishing an atmosphere which encourages open communication with both the ill child and the well children. Kaplan (1973) stresses that one of the primary tasks of effective coping in families with a chronically ill child is that parents gain a realistic understanding of their child's illness and communicate this within the
family. When parents deny the reality of the illness and avoid discussing it, ineffective coping results. However, as Steinhauser (1972) says:

> Often parents in their anxiety cannot allow the children, including the sick child, to openly raise any of their anxieties. Helping the parents face and master their own anxieties thus preparing them to tolerate and deal with the concerns of their children, can be crucial in minimizing serious and long lasting emotional damage (Steinhauser, 1972, p.327).

Several authors have shown a relationship between open communication and effective coping or, conversely, a relationship between poor communication and ineffective coping (Tropauer et al., 1970; Grossman, 1972; Kliman, 1978).

Vaughn (1957) found in his study of hospitalized children that those who expressed their feelings and views about the hospitalization and the operation and had their misperceptions corrected, showed much greater improvement, especially after discharge, than the control group. Similarly, Rie et al. (1964) found that children with rheumatic fever who had opportunities to talk about their feelings and explore their anxieties had better long term adaptation to their illness than did a control group who did not talk about their feelings.

Turk (1964) says the ill child is often aware of the demands his illness makes on other family members and if this
is not talked about openly, everyone becomes locked into a "web of silence," which can impair the psychological functioning of all family members.

In summary, two aspects of communication theory are pertinent to this study: (1) the important part perception plays in the individual's understanding of a situation, which has implications for professionals when communicating with parents of chronically ill children and also has implications for parents communicating with their chronically ill child and their well children and (2) the importance of helping individuals to express their feelings and anxieties, etc., which again has implications for health professionals supporting parents in talking about their feelings and encouraging them to help their children to talk about their feelings.

Families Coping with a Chronically Ill Child

The most classic study of families coping with a chronically ill child was that of Lindy Burton (1975) who interviewed 53 families of children with cystic fibrosis (all known cystic fibrosis families in Northern Ireland). Using an interview schedule, Burton focused on difficulties caused by raising a child with cystic fibrosis and the methods parents had used to overcome these difficulties. The findings most pertinent to this study were that the majority of parents did not communi-
cate well with any of their children about the illness.

Only 27 percent of parents of school aged children communicated well with the sick child concerning his illness. Out of 58 children with cystic fibrosis only about one half knew what the illness was called and only one third knew they would have it for life. Only one child out of the entire group had been told the disease was inherited. Burton reported that the majority of school aged children said they had never been able to confide in anyone about their fears. The most frequent reason given by parents for not talking about the illness was their desire not to hurt the child. Burton found that the child's prognosis was the biggest stumbling block to communicating about the illness.

Fifty-three percent of mothers in Burton's study denied discussing the illness with their well children, and in families where explanations had been given, they were very limited in nature. Parents rationalized that the well children weren't interested because they rarely mentioned the illness to parents or questioned them about it. Yet 39 percent of mothers and 26 percent of fathers said they thought their well children felt left out and resentful. Also 37 percent of mothers and 28 percent of fathers reported their well children had behavior problems such as rebelliousness, bedwetting, school problems, etc. While this was not a correlational study, Burton suggests
that the parent's evasive and inadequate communication may well have contributed to the problem behaviors reported in the well children. Burton concluded that it was obvious that many parents needed help in answering their children's questions and in giving age-appropriate explanations.

Cytryn et al. (1973) found in their study of 29 families of children with cystic fibrosis that almost all of the parents interviewed were unable or unwilling to talk to their ill child about his feelings. Even factual information was reluctantly or partially communicated. In none of the cases had parents been given help in examining their own feelings or those of their child about cystic fibrosis. The authors conclude that the results of their study indicate that such help should be made routinely available to parents. Unfortunately, the study reported no data on the well children.

Binger (1969) conducted a retrospective study of 20 families concerning the impact upon parents of living with and having a child die from leukemia. All parents were interviewed by a child psychiatrist within two years of their child's death. Parents described the diagnosis of their child as the hardest blow they had to bear throughout the course of the illness. In the first few weeks after the diagnosis, parents related feelings of depression, anger, hostility and self-blame. Denial was not experienced by these parents but they did report
encountering denial of the diagnosis by relatives, especially grandparents and friends. Binger found that the grandparents' anxieties and lack of knowledge made them ineffective supports for the parents. Fourteen parents admitted they tried to shield their child from the diagnosis; 11 of these children indicated their sense of impending death. The two families who did talk openly to their child about his illness reported they had a more meaningful relationship with their child than they had ever had. They attributed this to their frank discussions and open communication. Parents identified as sources of support: each other, personal religious concepts, the doctor, the social worker who offered practical assistance and a listening ear and other parents of children with leukemia. However, a few parents did mention their burdens were sometimes increased by inappropriate sharing of sorrows with other parents. All felt it was important to treat their child normally during the illness and all expressed a need for more time to talk to doctors about matters other than medical management of the disease. Although the study provided a good delineation of parents' feelings about and reactions to living with a chronically ill child, it is a retrospective study so parents' memories about living with the illness experience may not be completely accurate.

Tropauer et al. (1970) found in their study of chil-
dren with cystic fibrosis and their mothers that 9 out of 18 mothers said they had no discussion with their ill child or his siblings about the illness. Several children with serious cases of cystic fibrosis were not even told the nature or significance of their illness before adolescence. Mothers rationalized that this spared the child unnecessary anguish. These adolescents displayed embarrassment about their disease and tried to hide it from their friends. The authors said it appeared that the parents' patterns of deception and avoidance also became the child's style of coping with the illness. Also, in families where there was suppression of feelings and avoidance of discussion, projective tests administered to the ill child showed fears about dying. Mothers reported that sibling's resentment toward the ill child was more open and pronounced than in families where open discussion prevailed. Many mothers in this study complained about their husband's lack of participation in caring for the ill child and his disinclination to talk about feelings. The authors concluded that, in families where open discussion and mutual support prevailed, the child's illness had little disruptive influence on the family whereas the less communicative and less emotionally supportive family members were with each other, the more likely they were to exhibit difficulties in adjusting to the illness. It is difficult to know if the data from this study are characteristic of
families of children with cystic fibrosis since the families were selected for the study on the basis of their availability for psychiatric and psychological examination. Therefore, the selection may have been biased because of families volunteering so they could get help or, conversely, they may have refrained from volunteering due to anxiety about the possible test results.

McCallum & Gibson (1970) studied the adaptation of 56 families to having one or more children with cystic fibrosis; using detailed questionnaires, individual parent interviews and parent group discussions. One of their findings was that the parents' adaptation to their child's disease appeared to progress through four main stages: prediagnostic, confrontational, long term adaptive and terminal. In the confrontational stage (when diagnosis was confirmed) findings included parents' denial, detachment, avoidance and repression with prompt forgetting of the physician's communications about the diagnosis. This was often followed by random seeking of information from non-professionals. When parents began facing the reality of the situation a period of mourning ensued. Even with the long term adaptive stage parents fluctuated between denial and mourning.

Another finding was that in each successive phase of the child's development, critical issues arose with which parents had to deal. In infancy, feeding problems, bowel
training and resistance to postural drainage were identified as problems. Peak periods of protest were between 6 and 12 months and 24 and 30 months. In pre-school years, adjustment problems related to loosening intense attachments to parents were noted. Between 8 and 12 years, two critical issues were identified: one; sensitivity about being different from peers and resultant embarrassment about the disease and two; the child's emerging awareness of the prognosis. Yet 28 percent of school children were reported to have asked no questions; the other 72 percent asked such questions as: Will I ever get over it? What is wrong with my body? Will I die from it? Will I be able to marry? Will I be able to have children? Will my children have cystic fibrosis? Approximately one third of the parents in McCallum & Gibson's study avoided giving their child any information about his illness because they feared it would lead to questions about his prognosis which they would be unable to answer.

The authors concluded from their study that families of children with cystic fibrosis have critical issues to deal with at each stage of the child's development and that medical management, group discussions and parent interviews contributed to parents being able to deal with these issues. The discussion groups held for parents were called educational-supportive groups with emphasis placed upon interchanges among
members. Discussion included issues such as how to do postural drainage on a negativistic infant, how to explain the illness to siblings or how to deal with the anxieties of relatives. These discussions led to a variety of workable solutions for parents. The authors stressed that although feelings were discussed, there was a limit to the extent to which anxieties could be explored as they could readily threaten the defenses of others.

The data from this study appear to be a reliable and valid indication of how families adapt to their child's cystic fibrosis, as the information collected from each family was derived from at least two of three sources which were compared for internal validity. Although the study is called family adaptation to the child with cystic fibrosis, there are no data reported on the siblings of the ill child, even though the families studied included 87 siblings.

Turk (1964) in her study of the impact of cystic fibrosis on family functioning, did investigate how siblings were affected along with the other family members. Using a questionnaire with open ended and forced choice questions, she interviewed 28 parents to determine specific areas of social and emotional deprivation and problems in communication between family members. She found that 60 percent of parents never discussed the diagnosis with any of their children, including
the well siblings. Discussion was limited to the child's treatment and activities only. Turk said one would not expect such lack of discussion, especially since well siblings were expected to babysit the ill child, had their activities restricted because of him, and were deprived of family outings. At the same time, parents voiced concerns about their well children's behavior such as playing sick to get their attention. Turk also emphasized that parents failed to come to grips with these problems saying they would give attention to them later.

Turk recommended from her study that health professionals must help parents refocus on the needs of the whole family and not just those of the ill child. She also recommended that parents visit the physician together to prevent misunderstandings and increase appreciation and consideration of one another. This recommendation may have resulted from the father's lack of participation in the study. Only 3 fathers, as compared to 25 mothers, participated.

A few studies have focused mainly on the siblings of chronically ill children and the effect the illness has on their adjustment. Grossman (1972), in an extensive study of the college aged siblings of retarded children, found that effective coping of the siblings correlated positively with open discussion of the handicap in the family. She also found that healthy children sensed their parents discomfort in talk-
ing about the subject of their retarded brother or sister so they learned to get their information elsewhere or not at all. The main problem with the study is that it is retrospective so the reports of what the siblings thought and felt may not be an actual factual description of what went on in the past. Another limitation identified by the author is the possible bias of the sample due to better adjusted siblings volunteering for the study while those who were poorly adjusted may have stayed away. Despite these limitations, the data from the study correlated with the author's clinical findings over the years:

The individuals and families who adapt well to having a handicapped child are unashamed of the child, talk openly about his retardation and make a point of educating others about the handicap ... the extent to which normal siblings relate their handicapped brother or sister to their own outside world by talking about him, being seen with him, etc. reflects the way the parents deal with that issue (Grossman, 1972, p.81).

Iles (1979) found in her exploratory pilot study of the school aged siblings of children with cancer that the prevailing theme of their experience in living with a sibling with cancer was one of change, most of which was unexpected and for which there was no preparation. Only one child reported satisfaction with the information parents gave him regarding the illness experience. Several of the children reported that they got their information and support from sources other than their
parents, when they learned they could not get it from their parents. One child reported getting information about her sibling's illness at the public library; the librarian helped her look it up! When the well siblings were asked what would be helpful to them they all mentioned either having things explained to them or having someone to talk to. Iles says the data suggest that the impact of a child's chronic illness on healthy siblings is significant. Since the study was only a pilot study, the findings cannot be generalized in any way but they do point to the importance of assessing how well children are coping with the experience of living with a chronically ill sibling.

In summary, the literature documents the importance of information seeking and open communication in effective coping with chronic illness. Studies of families with chronically ill children demonstrate that many parents have difficulty communicating with their children about the illness. Yet there is little available research on how these families do communicate about the illness or the kind of guidance they have received from health professionals to help them communicate.

These deficiencies in the research literature lend support to the focus of the present study on how families with chronically ill children communicate about the illness and what guidance they have received in doing this.
CHAPTER III

METHODOLOGY

This study was conducted to describe communication patterns in families of children with cystic fibrosis and to identify what guidance parents had received in talking about the illness. The information could best be obtained by using an exploratory descriptive research design (Brink & Wood, 1978). This chapter describes the various aspects of the methodology used to conduct the study: sample selection, data collection and data analysis.

Sample Selection

A random sample was not obtained due to time constraints and the geographic location of the families. A convenience sample was selected from the cystic fibrosis outpatient clinic of a large urban hospital. Children attend this clinic every three months for routine check-ups. The criteria for eligibility were: the child with cystic fibrosis had to have been diagnosed for at least one year so usual communication patterns could be established, siblings were living at home, and the parents had a good command of the English language. The parents of the first 14 families to meet these criteria were approached by the investigator for an interview.

The investigator introduced herself, discussed the
purpose of the study as outlined in the letter of consent (Appendix A) and requested the agreement of both parents to be interviewed. Arrangements were then made to conduct the interview at the clinic in a private office, or if permission was granted, the investigator made an appointment to interview both parents in their home. Eight parents were interviewed at the clinic and 5 were interviewed in their homes. Written consent was obtained before each interview began. Only one family refused to participate in the study saying they did not talk about cystic fibrosis in the family so there was nothing to discuss.

**Data Collection**

The data were collected using a semi-structured interview with both open ended and closed questions (See Appendix B). The closed questions were to ensure comparable data while the open ended ones were to avoid restriction of responses (Brink & Wood, 1978). Three main content areas were covered in the interview schedule. All 3 areas were derived from the literature review of problem areas in communication about chronic illness.

The first content area was concerned with knowledge of cystic fibrosis - what the parent's knowledge was and what information they gave their ill child and their well children. Items 1 through 7 in the interview schedule pertained to this area. The second content area related to feelings and included questions on how the parents dealt with their own and their children's feelings about the illness experience. Items 8 through 12 pertained to this content area. The third area
concerned guidance received from professionals in talking about
the illness. Items 13 through 15 pertained to this content
area.

The interview schedule was examined by thesis com-
mittee members and two experts in the field, (a clinical
nurse specialist and a physician in the cystic fibrosis
clinic). Revisions were made and the schedule was then pre-
tested with 2 eligible families. The reasons for the pretest
were:

1. To familiarize the investigator with the use
   of the interview schedule.

2. To identify any problems the parents might
   have in understanding the questions.

Minor adjustments were made and the interview schedule was then
used with each family. Each interview was taped and the tape
recordings were transcribed verbatim and the transcriptions
were used in the analysis.

The interviews ranged from 30 to 60 minutes in length
with the majority taking approximately one hour. Eight of the
interviews were conducted in a private office at the clinic
with only the mothers participating as they were from out of
town. The remaining 5 were conducted at the homes of the
families interviewed. In 3 of the home interviews both parents
were present, in a fourth one, the husband cancelled out at
the last minute and the fifth was a single parent.
Objectivity of the participant investigator was fostered by using the standard interview schedule for all interviews and by self-scrutiny of the investigator. One of the pre-test interviews was discarded due to the lack of objectivity on the part of the interviewer. Also, time was set aside after the interview finished to follow up on any areas in which the investigator wanted to intervene; for example, when a mother reported that she did not know how to deal with her son's anger, the investigator spent time discussing this with her after the interview.

To increase validity of the answers given by parents, the investigator worded the questions so they had to state what they had said and not merely that they had said it; for example, "Have you explained ______ illness to him? What have you said?"

Data Analysis

The transcribed data from each interview were first organized into categories based on the content areas of the interview schedule. Then descriptive statistics such as frequency distributions, and measures of variation were applied to the data.

In summary, 13 parents were interviewed by the investigator using a semi-structured interview. The purpose of the interview was to elicit data about the communication patterns in families concerning their child's cystic fibrosis
and what help they had received in talking about it. The data were analyzed using descriptive statistics, namely frequency distributions and ratios.
CHAPTER IV

RESULTS

The first purpose of this study was to describe family communication about a child's chronic illness. The second purpose of the study was to identify what guidance parents had received or would like to receive from health professionals on communicating about cystic fibrosis.

Description of the Sample

Fourteen families were approached by the investigator, one of which refused, saying they did not talk about cystic fibrosis in the family. Two of the remaining 13 were pilot tested, one of which was discarded due to subjectivity of the interviewer. One other interview had to be discarded due to sound difficulties with the tape. This left 11 families for the sample, and included 40 family members. In 9 of the families only the mother was present for the interview. Two of the mothers were single parents, 4 were from out of town and their husbands were not with them, one woman's husband cancelled at the last minute and 2 others said their husbands would not want to participate. In the remaining 2 families both husband and wife were present but one was a blended family with a stepmother, so the father did most of the talking. For purposes of clarity in reporting the results, these 2 interviews were considered as
one parent each since either husband or wife answered the ques-
tions and there were no disagreements.

All 11 families consisted of one or both parents, the
child with cystic fibrosis and one or more siblings. In one
family with 2 children, both had cystic fibrosis. As shown in
Table I the age range of the 7 girls and 5 boys with cystic
fibrosis was from 5 to 16 years with the mean age being 10.4.
As Table II shows, the age of diagnosis ranged from birth to 12
years with the mean age being 3-1/2 years. Table III shows
that the number of siblings ranged from 1 to 5 and their ages'
ranged from 3 to 21 years.

TABLE I

Sex and Age of Child with Cystic Fibrosis

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<tr>
<th>Family</th>
<th>Sex of Child</th>
<th>Age of Child in years</th>
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<tbody>
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</tr>
<tr>
<td></td>
<td>M</td>
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</table>
### TABLE II

**Age at Diagnosis**

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</tr>
<tr>
<td>11</td>
<td>5</td>
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### TABLE III

**Number and Age of Siblings**

<table>
<thead>
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<th>Family</th>
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<th>Ages in Years</th>
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</table>
Findings

The literature review suggested that families of a child with cystic fibrosis do not openly discuss the illness within the family. The facts of the disease are often withheld from the children and the feelings created by the illness are not talked about. Items 2 through 12 of the interview schedule were designed to gather these data. Item 1 was to test parents' knowledge of the disease and Items 13 through 15 were designed to identify what support parents had received in talking about the illness and what would have been helpful.

The 11 families interviewed described difficulties in one or more areas of communicating about the illness.

Parents' Knowledge of Cystic Fibrosis (Item 1)

Only one parent out of 11 could be described as having a poor understanding of cystic fibrosis. To her cystic fibrosis was "stomach problems, constant colds and her digestive system is all screwed up." Of the other 10 families, parents' knowledge ranged from a fair understanding of basic facts to a detailed knowledge of cystic fibrosis, including current research in the field. One parent described the lung involvement and digestive problems but did not understand the hereditary factor. Another described the difficulties with the mucus producing glands but did not understand how organisms affected
the lungs. Three of the parents were very knowledgeable and the other 5 parents had a good understanding of the basic facts.

Explaining Cystic Fibrosis to the Ill Child (Item 2)

The researcher investigated how parents explained the disease to their child with cystic fibrosis as well as the other children in the family. For purposes of clarity, the two will be described separately, with how parents explained the disease to the child with cystic fibrosis being described first. Parents varied greatly in the extent of their explanations, from telling their children everything about the illness to answering their questions only, without expanding on them. All 11 parents said they gave their children some explanation of the disease, albeit, in some instances, very brief and all felt they had told them enough. All parents mentioned the name of the disease to their children.

Some parents waited for their children to ask questions and utilized this as a beginning point to explain the illness. This often occurred around 3 or 4 years of age, if the child was diagnosed in infancy. The explanation parents gave at this time was usually brief and evolved into more complicated explanations as the child got older and asked more:

When she was around 4, she started asking questions. I just told her if she didn't take pills, she'd have a
stomach ache. I don't think she'd have understood more. I think you can overburden a child with facts. Children are inclined to ask when they are ready. Now that she's getting older (8½ years) she has a lot more questions.

As soon as he was able to ask me questions (3 years) I tried to explain in terms that he would understand, what was happening to him and why we were doing certain things (like pounding his chest). As he's grown older and been able to understand in more depth, we've talked about it in more depth. I think this has gone a long way in alleviating any fears he might have about his condition.

At 3 years I just gave a brief explanation 'your chest is not like other people's and physio will keep it well.' We are gradually feeding him more and more every year. For instance he realizes now that his stomach sticks out so I explained why or he talks about being thin and I say that's because of such and such.

Other parents said they did not explain the illness at any specific age but that it had just evolved over the years:

Not that I've sat down and said you have cystic fibrosis and this is what it is. It's something we've just grown up with.

We just sort of slid into it. It wasn't any big deal like 'you have this disease called cystic fibrosis' - the name was there in the house, the doctor visits, the clinic.

I don't think I ever sat down and said 'I'm going to explain it to you.' It's
just bit by bit, a gradual breaking in. We don't put any great emphasis on it. That's life.

Not that we've sat down and explained. It sort of evolved through the years with us talking about it.

In contrast to these parents, 2 of the families presented their children with all of the facts:

I explained everything from day one. If she could talk, she could understand. I never held anything back, including her life expectancy.

He was diagnosed when he was 12 years old and I asked the doctors to explain it fully in front of him. I feel at his age he's old enough to take honesty and with it he'll have no questions lurking in the back of his mind that will frighten him more.

Despite the conviction of these 2 parents that explaining it fully was the best way to handle it, the one main theme which seemed to emerge from the other parents was how much to tell their children, especially in regards to life expectancy. The following statements clearly indicate the struggle these parents go through in making that decision:

I know some mothers who don't believe in letting their child know anything. I think this is wrong but I do believe strongly in not overdoing it. The only thing I can compare it to is sex. You don't want to say too much and you don't want to say too little.

It's hard to find a happy medium. You
don't want to say you won't grow up
but you can't say everything is okay.
Kids aren't stupid. They know.

Close friends of ours had a daughter
who died of cystic fibrosis - that was
very hard to explain to our kids without
scaring them or giving them too much
information. I really don't know how we
did it.

Every piece of cystic fibrosis litera-
ture I've read seems to stick out with
the words 'this usually fatal disease.'
I never say anything to my son (14 years)
but I'm sure he's seen some of it because
as soon as he sees the words cystic fibrosis
he immediately reads it. But I don't think
it sticks out for him like it does for me
because I've told him he has a mild case
and these words only apply to severe cases.

In the beginning we told him (at 7 years)
that he would outgrow it but the nurse con-
vinced us we should tell him the truth
before he found out. So I went back and
told him I'd been talking to the doctor and
I had made a mistake - that he wouldn't
outgrow it. He's never asked about life
expectancy but I think I told him he'd live
to be an old man.

One parent voiced with honesty what seemed to be the
fear of most:

My biggest fear is that he'll find out he
doesn't have as long a life expectancy as
other children. That's my biggest fear,
telling him or realizing he has discovered
it. I can't even foresee what I would say.
I would like to think I would be honest but
I don't know.

Only one parent out of 11 had told his child (7 years)...
that she might not live as long as other children. He felt that if she grew up with the facts, even if she didn't fully understand them, it would be less traumatic than laying a heavy trip on her "when she became a teenager." He compared it to the trauma of a child finding out she's adopted in adolescence.

Explaining the Illness to Siblings (Item 2)

Nine of 11 families said they gave all their children the same explanation, the most frequent reason being that they were all present when the illness was talked about. Only one mother specifically emphasized the importance of age-appropriate explanations. She stressed that she explained to each child at the age level she felt they were able to understand. Another mother said that the same explanation to both her children was fine until her well child went to school. At that time the children in his class made remarks which upset him so she had to give him a more thorough explanation. For instance, he came home one time very upset because someone told him his sister was going to die. He was only 7 and he thought it was going to happen right then. He thought he'd come home one day and she'd be gone.

Only 4 of 11 mothers said they had to repeat their explanations because questions kept coming up, or the children would often forget what they were told. Also, as one mother
pointed out, because misconceptions exist about cystic fibrosis, if her children saw something like that they always came and asked again.

Another aspect of explaining the illness to children was how parents handled the event of their ill child being hospitalized, both with him and the well children. Four of 11 parents said they explained in detail to the ill child and his siblings the reason for the hospitalization and what was going to happen. They expressed similar reasons for doing this - as long as the children knew ahead of time they were fine but if they did not know they became fearful and uncooperative. Two parents said they did not tell their ill child or his siblings ahead of time and both reported that their children were very frightened of hospitals. The other 5 parents gave some explanation to their children and reported that there were no problems with them. Two of these mothers emphasized their child's maturity (12 years and 16 years) as a major factor in their adjustment to hospital.

Only 2 families reported negative reactions in the siblings of the ill child. In both these instances the siblings were afraid their brother or sister would not come home again. This coincided with their realization that the ill child could die. However, the parents in both families talked openly to the siblings about it and said the fear passed.
Parents were also asked what they had explained to their children about clinic visits. In 8 of 11 families the siblings of the child with cystic fibrosis would occasionally go to clinic with him. If they asked questions at that time the parents said they answered them. Often they just sat and watched, saying little. When they didn't go to clinic the child with cystic fibrosis often came home with an explanation of what he/she had done. Only one of the parents reported that her well child would not go to the clinic with them or even talk about the illness (she is 16 years). The parent explained this behavior as resulting from a fear of doctors and hospitals.

Checking Children's Understanding of the Illness (Item 3)

Only 2 of 11 families said they had checked their children's understanding of the illness. One parent said that when it became evident that it was a bit of a problem around school age, she and her husband tried to get the explanation down to about 4 sentences so that their child could almost give it off by heart. This same mother said she would listen to the explanations he gave his friends and if he was having difficulty she would step in and help him with the explanation.

Are Parents Uncomfortable Talking About the Illness? (Item 4)

Only one of 11 parents said she was uncomfortable
talking about the illness and gave as her reason the fear of saying the wrong thing and causing her son to worry about it silently. Although 10 of the parents said they were not uncomfortable talking about it, most qualified this in some way. One mother said she used to be uncomfortable talking about it but once she and her husband "got straight in our own minds how we felt about it, we didn't have any problems explaining it to the kids." Another mother said she had no difficulty talking about it when her son was well but she couldn't talk about it when he was ill because she was too upset. Another said she didn't put too much focus on it because she didn't want to make her daughter feel depressed. Another mother said she was not usually uncomfortable but she did have a difficult time explaining to her children about their friend's daughter who died from cystic fibrosis.

Questions Asked by the Children (Item 5, 6)

Two parents reported that none of their children asked questions about cystic fibrosis. One of these mothers felt they just understood it, so they didn't need to ask questions. The other one said, "She's too young (11 years), I figure in due time she'll ask." In both of these families when asked if the illness had been explained, the mothers said if questions were asked, they were answered. Since there were no
questions it seems doubtful that it was talked about. Two 
other parents wondered at the infrequency of questions from 
their child since they were bright and inquisitive in other 
areas. However, both said they did not encourage questions, 
just answered them.

The questions asked by children in the other families 
seemed to fall into 2 main categories: The why questions of 
the 3 to 5 year olds, - Why do I have it? Why do I have to 
take pills and my friends do not? Why do I have to go to 
hospital? Why am I sick a lot? and the more searching ques­
tions of the 11 to 13 years olds; Will I die? Who will do my 
therapy once I leave home? Can I marry and have a family? 
Who will take care of me when I am older? Will my babies be 
sick? Would you still have adopted me if you had known I 
had cystic fibrosis?

Some of the mothers mentioned that their children 
accepted it more matter of factly when they were younger but 
as they mature they are becoming more aware and asking more 
questions, especially around the age of 11 to 12 years. One 
mother said her son did not ask questions when he was young 
because he was well. It was only when he became sick, at 
about 11 years, that he asked if he was going to die.

Parents were asked if they thought their children 
were getting information other than from them. Only 2 said 
they did not think so, 3 others were unsure but the other 6 
named specific instances where their children picked up
information - cystic fibrosis mail, T.V., clinic, summer camp. One mother said, "I know it must be hard for the kids when someone who was at camp the year before doesn't show up because they've passed away." Another said:

He certainly gets information at the clinic, even if he doesn't hear anything, he sees - some of the children who aren't so well; the coughing.

An issue of concern to some parents in regards to their children getting information elsewhere, was how to screen the information reaching the child. Two mothers said they screened the cystic fibrosis mail and if there was anything frightening, they did not let their children see it. Another mother was concerned about the information her child picked up at the clinic:

For years I've fought what they would say in front of that child and then give him back to you. I don't think they have the right to do that. I mean the parents are the ones that have to live with it.

Parents were also asked if they encouraged their children's questions. Only parents in 2 families said they actually brought the subject up for discussion. Eight parents said they answered their children's questions when asked and one parent said she did not encourage their questions since cystic fibrosis was just a normal part of their circumstances.

Parents' Conversation About the Illness (Item 7)

Four parents said they did not talk about their
child's illness with one another, although they had when the child was first diagnosed. As one mother said, "We talked a lot in the beginning because the biggest thing was just accepting it." Another said, "We talked when she was diagnosed but now we just do what we have to and don't dwell on it." For another family, most of the talking centered around the mother's second pregnancy: "It was always, 'I wonder, could we handle it again, go through it again.'"

Three other parents said they discussed only factual things about cystic fibrosis - the meetings, the clinic visits, the treatments, etc.; although with one family the "facts" became a battleground. Neither husband nor wife wanted to do the child's physio so they argued a lot about whose turn it was.

Only 4 of the parents admitted to talking about the feelings of having a child with a chronic illness. One mother expressed what others seemed to feel:

Probably the biggest thing we still discuss are the fears of A. getting sick. I know when he's been sick how hard it is. It goes on and on, and gets pretty scary because you don't know where it's leading. The fears are talked about, especially then - I think there is more of a tendency to have those kinds of discussions when he's sick.
Another mother said:

I get concerned about the future. R. missed 45 days of school last year and this year he's missed a fair amount. I keep thinking, 'how's he going to manage especially when he gets to junior high.' My husband just says, 'We'll work out those problems when we get there.'

As well as discussing the fears of their child getting sick, parents also focus on what they can do to keep their child well:

When he's well, the things we discuss are keeping him well - whether it's okay for him to play soccer in the pouring rain. You don't want to single him out but whether you should or whether you shouldn't.

Do parents have their conversations about cystic fibrosis in front of their children? If so, are they included in the conversation? Only 3 parents showed an awareness of not talking about certain things if the children were around. They emphasized saving such conversations for private times, and otherwise including the children in their conversation about cystic fibrosis. As one mother said:

If we're discussing it and they're around we include them but we feel that way about any conversation in our house.

In contrast, 3 parents admitted to discussing sensitive
issues when the children were around without including them.

Parents Talking About Their Feelings (Item 8)

Six parents said they did not talk about their feelings and the most frequent reason given was that their spouses would not talk about it with them. One woman said, "I need to talk about it but my husband just turns away from me." Another woman said:

My husband wouldn't talk about it at all and I became very depressed. I didn't want my son to see it so I kept quiet.

Another said they were just not a family to talk things over. Her husband just ... "figures I will be looking after it and that is the way it is with most things."

One woman talked of the difficulties of being a single parent:

It's tough when you're on your own. I would like to be able to talk to my sisters about B. but they don't want to discuss it. One just told me 'I can't handle it. I don't want to hear about it.' My brother doesn't want to talk - nobody wants to talk. No, I don't have anybody and you learn that over the years.

Of the 5 parents who did talk about their feelings, it was usually with their spouse. Two of them mentioned their
doctor and other parents of cystic fibrosis children as good resources for discussing feelings. One parent explained why his doctor was an important resource for him:

The only other person I really talk to is Dr. D. The one thing I like about him is he's a straight shooter. He doesn't hide anything. He'll tell you and that's really the only way I want to handle it.

Three parents mentioned that their friends and other relatives were not good resources for talking about their feelings:

There were people who didn't want to listen. I think some of our friends purposely stayed away because they didn't want to listen.

My husband's family won't talk about it. In fact part of their family don't even realise B. is sick ... I have friends but it's something you don't unload on friends. You don't want to drag them down with you.

You can't talk to your friends about it because you won't have friends too long.

Do parents share their feelings with their children? Six parents said they did not share their feelings with the children. As one put it, "No, they can't cope with it." Of the other 5 parents who did share their feelings, 3 of these qualified their, "yes", by saying they shared if they were in a bad mood; for instance. Only 2 parents admitted to
sharing their fears with their children:

Once I was crying and she (5 years) asked me why was I so worried about her and I just told her that her lungs were important and I didn't want her to get sick.

Sometimes when I get scared I get cross and I'll say 'come on, cough, cough, cough'. I just get so frustrated because I can't seem to get the mucus up. Then I'll apologize to him for getting cross and just tell him why - that I'm worried that he'll have to go in to hospital.

Talking to the Ill Child About His Feelings (Item 9)

Six parents said they did not talk to their child with cystic fibrosis about his feelings. The reasons given were varied. One parent said his child was too young yet to have many feelings about her disease (7 years). Another said their children didn't seem to get upset (5 years, 8 years). One mother thought it was better not to dwell on feelings so if her daughter looked "down" she would say or do something to shift her mind from it. In contrast, another mother tried to talk to her daughter but she said it was like trying to talk to a brick wall, "she just shuts herself off and keeps saying, 'well, I'm not sick.'" Another mother attributed her son's (8 years) reluctance to talk about feelings to, "boys are like that." She went on to say that she made very sure to explain everything to him even when he wasn't looking for answers or
information; because as much as he liked to play "Mr. Cool," inside all kinds of things could be worrying him.

... Only one of the parents said she didn't talk about feelings with her child, because she didn't think she could cope with it. This was a mother whose 11 year old son had suddenly said to her, "I hate you for giving me this disease and I'm going to die when I'm 12." Up until that point he had never talked about his illness and his mother was confused as to what had prompted this outburst:

I don't know why he said this to me
... inside is he really thinking that this is what is going to happen or is he questioning the ads he's seen or things he's picking up at the clinic and not wanting to believe it but testing me? I don't know. I wish I could open his brain and see what's going through his mind. He's a very clever boy and I wonder why he hasn't asked more questions and why all of a sudden there's a flare up like that.

She was very upset about how she had handled the situation and felt she had not said the right thing. She asked him where he got the idea that he was going to die the next year but he wouldn't discuss it after that. Since then she said:

I'll ask him sometimes if something is wrong and he'll say 'no'. I won't say anything more. ... maybe because I can't cope with it myself. I can under-
stand the anger. Someone has to be there for him to take his anger out on. That doesn't bother me. What bothers me is 'how do I answer him'? I'm very terrified to open my mouth in that I might just send him off on another frenzy. I'm not a psychiatrist, I haven't had any training in what to say to someone, especially someone you love so much.

Of the 5 parents who said they did talk to their ill child about his feelings, the most common feelings they reported their children experiencing were anger, depression, fear and embarrassment. Two mothers said they had long talks with their children at nights when they were up doing physio because of a cold. One said, "When he's sick, he's a little more open, maybe because we spend a lot of time together." Another said, "When she's sick she gets scared and we talk about it." Two other mothers said they acknowledged their children's feelings when they got upset but didn't discuss them at any length. One said, "I tell her I don't blame her for feeling frustrated and mad at having to have treatments all the time. Then she usually goes out and jumps out her frustrations on the trampoline." The other mother said "I just tell her that it's okay to feel bad, I understand."

One mother tells how receiving some guidance helped her to deal with her son's feelings:

T. (14 years) has very angry moods
sometimes. I remember one day in particular. He was so angry at everything. Nothing came out but frustration and anger for 2 or 3 days. I had been trying to reach him saying, 'What is making you so mad?' 'Why are you acting like this?' Finally, I was just about desperate and the cystic fibrosis newsletter came and there was an article in it, written by a nurse on anger - how it affects the child and how it affects the parents. It told me everything I needed to know - that he was angry at his disease and maybe at his parents for giving it to him. I talked to him about that and you know the anger just faded away. It was gone with that little talk and yet it had been so hard to find the key.

The feeling most frequently mentioned by parents was their child's embarrassment over his disease. Even parents who said they didn't talk about feelings mentioned their children's behavior in respect to trying to hide his disease from his friends. This embarrassment was clearly age related, beginning usually around 6 or 7 years and lasting until 11 or 12 years, at which time the child began to test his friends by sharing his secret with one of them. If there were no repercussions from letting the secret out he/she usually became more open.

One mother told how her daughter began this testing at 11 years:

She used to say when she met someone new, 'I'm not going to tell them what I have or they won't be my friend.' She seems to be getting over that because she just met someone new and
she told her what she had and then said 'She's going to be my friend anyway.'

Another mother said her son, 11½ years old, hid it until recently when he and his friend were watching the Handicap Olympics on T.V. and he then took his pills in front of his friend. She thought it might have been related to the fact that his friend seemed very compassionate toward the handicapped and her son felt he would accept it.

Two other parents mentioned that, when their children were around 4 or 5 years, they had been quite proud of the fact that they had something no one else had. That changed, however, when they reached 7 or 8 years, and they no longer wanted to talk about it. Another parent said her daughter who is 5 years still tells her friends; in fact, in a show and tell session at kindergarten, she did physio on her classmates.

Parents varied in their way of handling their child's embarrassment. While some respected their child's wishes and didn't mention the disease, others refused to go along with it. One mother said:

He (12 years) wouldn't carry his own pills because they rattled in his pocket. If we ate out I had to pass the pills under the table because he didn't want anyone to see him take them. I used to go along with him but finally I thought, 'No, I'm acting as
though there is something to be ashamed of so I passed them over the table and said, I'm not going to hide these anymore, T., I have nothing to hide.' He gave me a funny look but now he takes them in public.

Talking to the Well Children About Their Feelings (Items 10,11,12)

Six parents said they didn't think their well children felt jealous or resentful of the time they spend with their child with cystic fibrosis. The fights the children had were attributed to normal sibling rivalry and nothing was made of them. The reasons parents gave for this lack of resentment were: age of siblings, spouse involvement, size of family and amount of time spent with the child with cystic fibrosis. For example, jealousy was much less likely to occur in a large family where children were used to sharing time and attention, whereas with only 2 children, the well child would be much more aware of the time and attention spent on the other child. Another example is if the child with cystic fibrosis has been generally well, this would involve much less of the parents' time and energy than if the child was frequently sick. One mother explained why she thought her husband's involvement was an important factor in preventing problems in their well child:

My husband helped a lot. He would take X (well child) fishing or for long walks in the woods. He pro-
vided a lot of one to one for him
that I was unable to provide. Then
he would sometimes take over with
W (sick child) to give me the
opportunity to spend time with X.

Five parents felt their well children did mind the
time they spent with their child with cystic fibrosis. This
was indicated by their children's bids for attention through
acting out, as well as their verbal expression of resentments
against the ill child. Parents generally handled this by
explaining to their children why they had to spend more time
with their other child and making a conscious effort to spend
extra time with their well children. One mother said they
learned very quickly not to commit themselves to taking the
children somewhere because sometimes their child with cystic
fibrosis just wasn't well enough and then their other child
would be disappointed and resentful of her for spoiling the
outing. Another mother took her well child to the hospital
with her and the ill child so she could maintain contact with
both of them.

One parent identified as a source of jealousy their
friends' extra attention to their child with cystic fibrosis
while almost ignoring the other child:

... That has been a big problem with
the kids. When relatives or friends
come to visit they say 'Oh, how
is J.' and give her a big hug and
kiss and then say 'Oh, hi, B.'
This can really present a problem
to the other child.

Another parent talked of how her sick child used his
illness to get his own way:

G. also had asthma and if he got
emotionally upset it got worse so
if T. had a toy and G. wanted it,
he kind of had T. over the barrel
and me too in a lot of ways, so T.
had trouble holding back and not
pushing him around. He'd give in
and feel annoyed about it.

Three parents said they involved their well child in
helping with their ill child's treatments. One boy who was 8½
years had been responsible for seeing that his sister, 7 years,
took her pills. Another child who was 7 years sometimes gave
physio to her 11 year old sister, and a third girl (9 years) was
asked to show extra care and understanding when her brother was
crabby because he wasn't feeling well. Only one of these
parents felt some reluctance to giving her well child extra
responsibility: "I don't like to put pressure on her to feel
that she always has to be caring, but when he's not feeling well
..." Two of these 3 parents were in the category of parents
who felt their well children did resent their time and atten-
tion with their child with cystic fibrosis.
Receiving Guidance From Professionals (Item 13, 14)

One parent only said she had been given guidance specifically related to discussing cystic fibrosis with her children. This was in Montreal when her child was diagnosed and she and her husband were given a questionnaire guide to fill out. It included questions they might have about the disease. They were to study it, fill in the answers and then discuss with their doctor about how to handle it and what to say, etc.

Of the 10 parents who said they had not been given specific guidance, 2 said they had been given a lot of information when their child was diagnosed but they could not remember most of it:

It was explained to us thoroughly in the beginning but it was kind of a shock to start with. We tried to grasp as much as we could in one hour but we went out with our heads spinning. When you're upset like that someone can talk to you for hours and you don't remember. We had so many questions afterwards.

None of the parents had received information on age-appropriate explanations for their children and while most had no comment on whether it would have been helpful, one parent said it definitely would have been, "I just stumble along and play it by ear." Another parent felt the opposite way:
Nobody has and I don't think anybody can or should. I don't think anybody has that right. It's your child and you decide when they are ready. People are so different. It depends on the child, what he can handle. I mean how can they come out with a pamphlet that says 'Your four year old should have this much information about cystic fibrosis.' A child that is emotionally unstable can't handle it at four years. It depends on the child and it depends on the parents.

What Has Been Most Helpful? (Item 15)

The list of who or what has been most helpful to parents in discussing their child's illness is long and varied but the three sources most frequently mentioned were other parents, having information about the disease and the family's own philosophy or spiritual beliefs.

Although talking to other parents on an individual basis was cited as a significant source of help, parents seemed divided on the usefulness of parent groups. Some felt that comparison of children would occur and this could be upsetting for those whose children were not doing so well. Others felt that groups were too depressing because there was too much focus on the illness:

I feel my outlook is better by not being involved (in a cystic fibrosis group) and if D. knew I belonged, it would be focusing too much on her and she might think 'Why me, why not my
sister who has a blood ailment? In a way it would make it seem more serious. By being involved you would put a lot of serious thought into it that you wouldn't otherwise. You just can't live by dwelling on a thing.

One parent who was active in the cystic fibrosis organization told of the problems they had keeping people in the organization:

We have big meetings, sit down and discuss cystic fibrosis and people don't come back. You call them and say 'Why don't you come back to the meetings?' and they say 'we've got enough problems at home with cystic fibrosis - we're having troubles handling our own problems, we don't want to go to a meeting to discuss problems.' They don't want to get involved in talking about cystic fibrosis.

However, some parents felt that their contact with other parents through conferences, cystic fibrosis meetings or parent groups was helpful. One parent said just knowing he was not alone was a big help to him but also parents who have had years of experience with their children with cystic fibrosis could offer the kind of support he needed at times.

Another important source of help to parents was information about the disease. A number of parents said they knew nothing about the disease when their child was diagnosed and getting all the information they could became an obsession
The biggest help is completely understanding, having all the answers.

When I don't know what's going on, that's the only time that I've really felt scared.

The thing I appreciated the most is that I was never given the runaround. When I asked I was answered and I think that's important.

One parent, only, mentioned the great support her extended family had been:

If we hadn't had that kind of support, I think we would have had a lot more difficulties. But a lot of the little things are taken care of which takes a lot of worries away so the big ones aren't so bad then.

In contrast, a few parents said their families were not good supports, often denying the severity of the disease and saying they did not want to talk about it.

Parents' philosophy or spiritual beliefs often centered around normalizing their child with cystic fibrosis and focusing on the present rather than the future. One parent belonged to "Alanon" and she applied a lot of the principles of that organization to living with cystic fibrosis: "Living one day at a time is the important thing because with a disease like this you can really let your imagination get away from you."

This same parent had polio when she was younger and she felt
that also helped her to deal with cystic fibrosis.

It's a handicap and we can all learn to live with handicaps. We have to work around them and know our limits but we can still lead a normal life.

Many parents expressed the wish not to have their child singled out but to treat him normally:

Cystic fibrosis is a long way down on the list of who R. is.

We never forget but we treat it and live as normally as we can. We do everything to keep her healthy that we can. What else can you do - whether it's a cystic fibrosis child or a normal child?

We try not to make a big issue out of it, because you have to live your life and you can't have it centered around something like that.

One parent exemplified the importance of attitude/philosophy in coping effectively with a chronic illness.

I don't feel longevity means happiness. I don't think perfect health means happiness. I think there is an awful lot more to it than that so I never felt that this was a terrible thing that had happened. The one thing I certainly felt was, 'Okay, my son has an illness. There is something I can do about it. I wasn't helpless in that situation. I was able to do physio, I was able to give him support and to help him understand how to live with his illness. I can remember the first day I brought him home after he was diagnosed. I had to do the physio and he was in a mist tent. My
husband came home and all I had done that day was physio and the mist tent. I said to him, 'I'm going to have to get faster at this' because the dishes were left and the beds were unmade. You know, when you come home with a new baby, your first experience of trying to work out formulas and bottles, bathing him, and you're gingerly trying to hold him and you don't know what to do. Within 6 weeks it's as if you've been doing it all your life. It's exactly the same with cystic fibrosis. Of course there are times when it's inconvenient to do physio etc. and you may wish you didn't have to do it but don't we feel that way about dishes, washing the car, vacuuming. It's just part of life.'

What Would Have Been Helpful?

Five parents didn't know what would have been helpful. One of them seemed a little sceptical about how helpful health professionals could be:

As for receiving instruction, (in discussing the illness) I think it would have been helpful but it's hard because there is no happy medium. I think maybe in some cases the medical profession try to be too much help, sort of afraid they're missing a role somewhere. But again some parents like a lot of concern and help. I like a lot of privacy.

Other parents went back to the time of their child's diagnosis as a point where they needed more support. Parents telling their own stories would perhaps illustrate their needs the best:
When B. was born she had to have surgery and my wife and I were sitting in this little waiting room and the doctor walked toward us. We looked at him and both of us said at the same time 'she's dead,' because of the look on his face. He said 'she survived the operation okay but we suspect cystic fibrosis.' We didn't know what that was and he wouldn't explain it to us. He said, 'We don't know for sure, we'll have to wait until she's 3 months of age before we can do the sweat test. We don't want to worry you until we are positive and then we'll explain it to you.' No matter who I talked to I could not find out anything. I didn't have a clue what it was, not a clue. Finally we went to the clinic and got some pamphlets and read them. Sure it sounded bad because they are laying a bunch of heavy statistics on you but at least we had an idea of what it was. You know things bother me a lot more when I don't understand them.

This parent went on to say that it would be helpful if there was a pamphlet that explains what cystic fibrosis is from the parents' point of view - designed for parents by parents. He said the ones given him and his wife were just a bunch of statistics.

Some parents thought they were told too much and others thought they were told too little:

I remember them saying over and over again 'he mustn't catch colds or get the flu. He shouldn't be around other children! For almost a year I kept him away from everyone and then thought 'I can't live like this.' I think a lot of
it is to make you realize but you can't cope with all that in the beginning.

If the doctors could be just a little more specific when they are first explaining it to you. I went home with some awfully big questions on my mind. He just said 'It's a disease of the lungs and pancreas I called him the next day and said, 'I don't know what you are talking about.'

Another parent was shocked at the manner of the doctor who informed her:

The first question she asked me, point blank, was 'Are you very well off?' I had never heard such strange medical talk in my life and I said, 'Well, we're just ordinary people,' and she said, 'because D.'s treatment is going to be very expensive and she is very ill and her life will be seriously _____,' Ah, what she meant was shortened. That was the first I knew that cystic fibrosis was that serious. I don't think it's normal for a doctor to tell someone news like that over the phone, in that way.

Another mother said it would have been helpful if her son had been diagnosed sooner; he was 12 years old when diagnosed:

T. coughed constantly and there wasn't a year that went by, from Grade 1 that I didn't have a teacher phone me or write to me and say 'would you please tell T. to stop coughing because he's disturbing the class.' I took him to the doctor many times but the doctor would say 'there's nothing wrong with him. It's a nervous cough.' And so
we would be down his neck to quit and the child couldn't quit. And I'm sure that did a lot of emotional damage. His school work, after he was diagnosed, came up just dramatically. But he was feeling so much better because we knew what to do for him.

Other parents talked of the relief of just having their child diagnosed so the uncertainty of not knowing was removed.

Some parents mentioned the school system as an area where support was needed. They felt that teachers were often not familiar with cystic fibrosis and sometimes created undue anxiety for the child. One mother told of the scene made by teachers when her daughter dropped on of her enzyme pills on the floor. They accused her of bringing dope to school. Some parents made a point of going to school and explaining their child's illness to new teachers but others left that up to the child himself.

Some parents said that having someone to talk to would have been helpful for them. These were parents who admitted to having a lot of feelings about their child's illness but no-one with whom they could share them.

In summary, the findings reveal that parents do have difficulties in communicating about cystic fibrosis within the
family and they are not receiving guidance from health professionals in this area. They cite their own philosophy/religious beliefs, other parents and having information about cystic fibrosis as most helpful in helping them talk about the disease. They single out the time of diagnosis as being a point where they specifically needed more support and guidance from health professionals.
CHAPTER V

DISCUSSION OF FINDINGS

The findings will be discussed in relation to the conceptual framework and existing knowledge in the field. The discussion will be organized under the three main content areas covered in the interview schedule. The first content area was concerned with knowledge of cystic fibrosis - parents' knowledge and how they discussed the facts of the disease with their children. The second content area related to feelings - how parents dealt with their own and their children's feelings about the illness experience. The third content area concerned guidance received from health professionals in talking about the illness.

Parents' Knowledge (Item 1)

The researcher asked parents to explain what cystic fibrosis is to determine if they had adequate knowledge to communicate effectively with their children about the disease.

A general assessment was made of parents' knowledge based on the completeness and accuracy of their facts about cystic fibrosis. For example, if parents gave a complete description of the etiology, pathology, prognosis and rationale for treatment, they were considered to have a thorough understanding of the disease. If they could not accurately describe
any of the above factors they were considered to have a poor understanding. If they could describe some of the factors; for example, the pathology and treatment but not the etiology, they were considered to have a fair understanding.

Most of the parents in this study had a good understanding of cystic fibrosis, with some parents needing clarification in certain areas. Many parents mentioned that although they had been given detailed explanations of the illness when their child was diagnosed, they were unable to retain much of what was said due to their shock. This corresponds with reports in the literature that parents, at the time of diagnosis, retain only the information which helps them deal with the immediate situation (Friedman, 1963; Burton, 1975). Binger (1969) found that parents equated the time of initial diagnosis of their child with that of the child's death in terms of crisis.

The majority of parents emphasized the importance of gaining information to help them cope. Some parents followed up on the initial explanation they received by seeking out more information either from their doctor, the cystic fibrosis foundation, other parents or the library. This compares with Hoffman & Futterman's (1971) findings that parents of a chronically ill child often seek information as a means of getting some sense of mastery over the situation and to combat their sense of helplessness. It also compares with findings reported by Hamburg & Adams (1967) that parents go through stages in coping with chronic illness. The initial denial, while
decreasing the amount of information they absorb, permits them to make a gradual transition to acceptance of the diagnosis. When they begin to face it they seek more information about the illness.

However, in this study, some parents seemed reluctant to question their doctor. One woman who sought out more information herself talked of those parents who did not:

I have spent a lot of time with other parents discussing the disease and what they should know. I found an awful lot of very uneducated parents who didn't know anything about the disease and were too scared to ask; the doctors were gods to them. I happen to be very open myself so I pushed to get the information I wanted.

These findings point to the importance of families having follow-up conferences after the initial diagnosis is made so the understanding they have about their child's illness is accurate and complete.

The investigator expected to find a relationship between parents' level of knowledge and their communication about the illness but such a relationship was not found. Obviously, the parent who had a poor understanding of the illness did not communicate effectively with her children, but this was also true of some parents who had a thorough understanding of cystic fibrosis. Thus, while knowledge is a necessary condition for communicating effectively, it is not a sufficient one. There must be other factors which play a
part in determining how parents will communicate with their children; probably an important one is the parents' feelings/perceptions about the illness. Arnold (1978) emphasizes the importance of discussing with parents the personal significance of the knowledge they receive - what it means to them to be parents of a child with a chronic illness. Other authors have validated the importance of checking out the family's perception of the illness experience (Leventhal and Hersh, 1975; Korsch, 1971; Kaplan, 1973).

Another aspect of parents' knowledge which needs further exploration is whether the husband and wife receive their information together or separately. In this study, only 2 of 11 husbands were present for the interview, and, in most instances, the husband rarely came to the clinic. Regardless of the reasons for the husband's absence, this has important implications for family communication. If the wife is the only one in contact with the health professionals, the family is dependent upon her to convey information accurately to them. Friedman (1963) found that women who had the responsibility of keeping their husbands informed recognized there was a limit to how much they could retain after talking with professionals. In addition to improving the accuracy of perceptions, Turk (1964) emphasizes that if parents see the physician together, this could lead to more appreciation and consideration being given to one another. One woman in the present study, referred to this:
We still can't talk about it (their) child's illness) that much. I would have liked him to come to the clinic with me and I think he would have, except he couldn't get away. I thought it might be good for him to see that there are others who have to work with this.

Another advantage of parents seeing health professionals together is to reduce what Kaplan (1973) calls discrepant coping. This occurs when parents take opposing positions on how to cope; for example, they disagree on whom to discuss the illness with and what to tell others about it. Kaplan says this can produce garbled and dishonest communication about the illness. It is difficult to assess if parents in this study displayed discrepant coping since, in the majority of cases, only one parent was interviewed. However, in the 2 families where both parents were interviewed, they did agree upon how to communicate about the illness. This is assuming, of course, that they were being truthful and not merely wanting to present a "united front" for the interviewer.

Although in some cases it is very difficult for fathers to come to clinic, it was found in families of children with cancer that the father often deliberately avoided much involvement with his family (Binger, 1969). While this is a coping mechanism on the father's part, states Binger, it is not a wise one since it may have a negative effect on other family members. Binger emphasizes that these fathers need support to express their feelings and cope more effectively.
Discussion of Facts (Items 2-7)

The literature often refers to the conspiracy of silence which characterizes families of chronically ill children. While this finding was not generally supported in the present study there were areas certainly where it applied; for example, the child's prognosis. Telling their child his prognosis was a major concern for most parents. They were in a dilemma about whether or not to discuss it with the children, while recognizing that sooner or later the children would find out. Most parents felt that shielding their child as long as possible from the prognosis outweighed the possible negative reaction he might have when he found out he had been deceived. Binger (1969) says the question is not whether to talk about the diagnosis and prognosis but rather how to let the child know his concerns are understood and shared by his parents and that they are willing to talk about them with him. Van Eys (1979) states that "mental health of a child with cancer is living at ease with the reality" (Preface).

Although many parents did not specifically explain cystic fibrosis to their children, or give them many facts, they all thought they had told them enough. Since this study did not test the children's knowledge or perceptions it is difficult to determine the effect on the children of being given little information. However, many authors emphasize the importance of the child having realistic knowledge about events which affect him (Kliman, 1978; McCallum, 1975; Van Eys, 1979).
It is interesting to note that, while many parents mentioned that getting information about the illness was an important factor in helping them cope, only 2 of 11 mothers emphasized the importance of giving their child information to help him cope.

It is also interesting that parents stressed how the information they received needed to be repeated because they did not retain it, yet 7 of 11 parents said they never repeated the explanations they gave their children.

As mentioned previously, it is important to check the parents' perceptions of the illness experience. It is even more important to check the children's perceptions since young children, especially, are susceptible to many misperceptions (Wolff, 1969; Mattsson, 1972). Yet only one of 11 parents checked their children's understanding of the illness. One father who had explained cystic fibrosis in great detail, including the prognosis, and thought his children really understood it, found out differently. When he asked them what they thought cystic fibrosis was, he found his daughter (7 years) who had cystic fibrosis thought she would outgrow it and his son (9 years) had very little understanding of the disease.

Another instance in which checking out the child's perceptions is important is when the child is resisting treatment. One mother tells of her daughter's resistance to taking her medications despite detailed explanations by the doctor of why she should:
Dr. Z. made diagrams for her; he cut down every bit of food into fats and enzymes; how many enzymes she needed to cut down a piece of fat and how many to cut down a piece of protein. He ripped up half a sketch pad with all these diagrams and it didn't fizz on her. She still won't take her pills.

Despite these detailed explanations no one checked out the adolescent's perceptions of her illness. Wolff (1969) says the most successful approach to take with a child who is resisting treatment is to avoid reasoning with the child about how important it is and focus instead on how he feels about being a diabetic; for example. Explore his views about how the illness is affecting his family and what the implications are for his future. Such a process of exploration frequently uncovers surprising errors and misperceptions, the correction of which brings relief. Tropauer et al. (1970) concluded from their study of children with cystic fibrosis that arbitrary handling of resistance to treatment tended to make the child even more resistant since it failed to deal adequately with the underlying anxiety. Again this emphasizes that people often have different perceptions of a situation which do not get exposed unless one specifically checks them out.

Asking parents if they had checked their children's understanding of the disease may well have been the most important question asked. No matter how much knowledge the parent has or how much information he gives his children, if they do
not perceive it correctly, the communication is ineffective.

Another aspect of discussing the illness with children is how parents explained hospitalization of the ill child and clinic visits to their children. These situations can provide opportunities for discussion of the illness but were not utilized as such in this study. Siblings who went to the clinic with the ill child and their mother usually sat quietly on the sidelines and were not included in the visit. Although the ill child and his siblings were given an explanation about the hospitalizations when they occurred, this seemed to be an area where siblings could use extra attention, especially in checking out their perceptions about what is going to happen to their brother or sister. In 2 of the families interviewed the siblings were frightened that their brother or sister would not come home again.

Children are naturally curious and if they are not asking questions there is usually a reason. (McCallum, 1975). In this study, 2 parents reported that their children asked no questions and 2 more said their children rarely asked questions. Vernick and Karon (1965) found in a study of 150 children ranging in age from 3 to 20 years that children waited for adults to anticipate and deal with their serious concerns - only then would they reveal their pre-existing worries. Thus it would seem in families where the children are not asking questions that it is a indication that communication is not open or effective.
Discussion of Feelings (Items 8-12)

Many authors emphasize the fact that parents need an opportunity to talk about their own feelings before they can allow their children to talk about theirs (Wolff, 1969; Grossman, 1972; Lerken and Harsakis, 1973). In Burton's (1975) study parents who were able to talk about their worries concerning the illness stressed that it had a definite therapeutic value for them. Burton states that in all cases where parents were emotionally uncomfortable with the disease their ability to communicate with the child was diminished significantly.

Over half the parents in this study did not talk about their feelings with anyone. They often stressed that their own families, including husbands, parents, brothers and sisters, as well as friends were not good resources for them when it came to sharing their feelings. Thus, in many instances, they felt they had no one to turn to.

Only 2 parents admitted to sharing their feelings with their children, yet most admitted to displaying feelings at some point when the children were present, especially around the time of diagnosis. Also, some parents said they discussed sensitive issues when the children were around without including them. One mother said that during her second pregnancy she and her husband often discussed in their daughter's (7 years old) presence, whether or not they could handle another child with cystic fibrosis. At the same time, the daughter "shut herself off and refused to take her pills, saying, 'I'm
Another mother said she and her husband frequently argued in front of their daughter (11 years old) about whose turn it was to do her physio. Mother complained that this child was very uncooperative about having her physio done.

Kliman (1978) says even very young children are aware of and sensitive to significant changes in the attitudes and behaviors of those around them. When parents do not acknowledge these feelings to their children, they develop anxiety and, in the case of the young child, misperceptions about the reasons. Kaplan (1965) stresses that children cannot and should not be shielded from all the family worries especially if they are affected by them. Since a major developmental task is to learn to face reality and to tolerate stress, Kaplan says the family is the best place to learn this.

Studies have shown that the opportunity for children to discuss their feelings and anxieties reduces the likelihood of their showing emotional disturbances (Wolff, 1966; McCallum, 1975; Kliman, 1968). In the present study over half the parents did not talk to their children about their feelings. In a couple of instances parents expressed feelings of inadequacy over how to deal with their child's feelings when confronted with them. One parent, whose son was 11 years old, was confronted with, "I hate you for giving me this disease and I'm going to die next year." The parent said she did not deal with it in a way which helped her son and she is terrified it will happen again. Klimen (1968) emphasizes the importance of the
child having an opportunity to release feelings frequently and in small doses to prevent a build up and explosion of emotions which could be overwhelming to both him and his parents. The mother and son mentioned above are a good illustration of this.

The feelings parents reported their children expressing—anger, depression, fear and embarrassment, correlated with those found in other studies (Binger, 1969; McCallum, 1970; Wolff, 1966). Different feelings seem to surface at different times; for example, embarrassment was common around 7-8 years when the child's peers took on a new significance for him and depression often correlated with the child's beginning awareness of the permanence of death, around 11-12 years. This points to the fact that the child's illness has special emotional, social and intellectual meaning for him and his family in each stage of his development (McCallum, 1975) and the need for ongoing assessment is critical.

Although the literature findings suggest that siblings of chronically ill and handicapped children do have a number of negative feelings and resultant behavioral problems (Travis, 1976; Mattsson, 1972; Cain, 1964; Turk, 1964), over half the parents in this study reported no difficulties with their well children in this regard. Whether this is indeed the case, or whether as some authors suggest (Klein, 1974; Craft, 1979), the parents underestimate the impact of the chronically ill child on the well children, is difficult to assess. Answers may have been provided if the well children had also been interviewed.
However, reasons given by parents for lack of sibling problems - age of siblings, amount of time spent with ill child, size of the family, concur with findings of other studies (Burton, 1975; Travis, 1976; Jan et al., 1979).

Of the families who did report that their well children had difficulties, most parents dealt with the problem by explaining to the children why they had to spend so much time with their ill child. None of the parents said they actually spent time talking to their well child about his feelings. Many authors emphasize the importance of parents allowing siblings to openly express their negative feelings toward their ill brother or sister (Yamanato, 1972; Steinhauser, 1977; Jan et al., 1979).

In the one study of siblings' perceptions of the experience of living with a chronically ill child, they all made reference to wanting someone to talk to about their feelings and having things explained to them (Iles, 1979). Although this study was exploratory and had a small population, these findings do suggest that siblings of chronically ill children need more attention. Some authors suggest that assessment of the family with a chronically ill child should include an inquiry about how the well children are doing, what questions they ask and what answers they receive, etc. This may help parents to focus more on their well children's needs (Craft, 1979; Mattsson, 1972).
Another factor identified in the literature which contributes to sibling difficulties is their having to assume too much responsibility for their ill brother or sister (Burton, 1975; Grossman, 1972). In this study, 2 parents did seem to be expecting a great deal of their well child. In one instance an 8½ year old was responsible for seeing that his younger sister took her pills and a 7-year old was sometimes expected to give her sister physio. One would wonder how the siblings would feel if their brother or sister became very sick. Would they feel that they were to blame? Children, especially below the age of 8, display animistic thinking and often believe they are the cause of events (Wolff, 1969). It would seem that giving them responsibility for their ill sibling's care could create a great deal of unnecessary anxiety.

Guidance from Health Professionals (Items 13-15)

Ten of 11 families in this study were not given specific guidance from health professionals in communicating about the illness. It is interesting to note that, while some parents admitted to needing guidance, others did not. It would appear that the majority of these parents do not recognize the importance of their children having a thorough understanding of cystic fibrosis and the opportunity to talk about their feelings concerning the illness. Thus, guidance needs to begin with helping parents realize that all their children will have a greater probability of coping effectively if they have a thorough understanding of the illness and can talk openly about it.
Most parents did perceive the need for more guidance at the time of their child's diagnosis. Generally, they wanted more information about cystic fibrosis but they wanted it gradually and not all in the first interview. Some parents also perceived the need for guidance in helping their children deal with their feelings.

Although parents had received little guidance from health professionals they had found their own sources of help in discussing the illness; mainly, other parents of children with cystic fibrosis and their own philosophy/religious beliefs. This concurs with literature reports of sources of help to parents (Binger, 1969; Burton, 1975).

Although most parents cited other parents as being helpful in talking about the illness, they were divided on the usefulness of parent groups as a means of accomplishing this. Many preferred a one to one contact for the sharing of feelings. Since most parents voiced a need for information perhaps parent education groups as opposed to groups for discussing feelings would meet the needs of a wider population. The parent education group could focus on such things as communication skills, information about the disease, budgeting finances, community resources, etc. The discussion of feelings, concerns, problems, etc. could be dealt with on an individual basis.

The need to normalize their child was an important aspect of parents' philosophy and one of which health professionals should be aware. Often there is too much focus on the
child's illness and not enough on the well aspects of the child. Some families in this study made reference to this:

I have to admit, I've found this place (the clinic) depressing. There was always something hanging in the air. You felt that they were thinking 'be thankful we have some time to work with, hopefully to find a cure before she dies.' This was the feeling I got here - I wish they would look more like it wasn't quite so serious. Once you understand the illness, it may be serious but you've faced it and what more can you do but stop worrying about it.

They put such a scare into you that you feel every day something is going to happen. I was very uptight and it took at least 2 years to undo that. I got to the point where I hated the clinic.

Van Eys (1979) emphasizes that the home, school, hospital and clinic must be such that the child can live a full life and not primarily experience a disease that must be treated, "There is so much more to being a child than having cancer." (Preface vi).

Perhaps the most important point that came from asking parents what would have been helpful, is that, while there are similarities among people, each family is different and what is right for one is not necessarily right for others. One woman's statement reflects this simply: "Some parents like a lot of concern and help, I like a lot of privacy." Embleton (1979) stresses the importance of this concept in her work with children with cancer and their families. She says that, while it is good for some people to discuss feelings, for others it
creates more stress and we need to be careful not to push what is right for one as being right for all.

For health professionals to be helpful to families with chronically ill children, they need to listen to the families in order to discover what meaning the illness experience has for them. In this way the uniqueness of each family's experience can be combined with the commonalities which most families share, so that appropriate and timely services can be offered to every family.
CHAPTER VI

SUMMARY, CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS FOR FURTHER STUDY

This study was designed to elicit information about communication patterns in families with a chronically ill child and to identify what guidance parents had received from health professionals in talking about the illness with their children. A convenience sample of 11 families of children with cystic fibrosis was used for the study. One or both parents were interviewed.

The data were collected using a semi-structured interview schedule with both open ended and closed questions. The interview covered 3 main content areas related to communication; how the parents imparted information about cystic fibrosis to the ill child and the well children, how they handled their own and the children's feelings and what guidance they had received from health professionals in talking about the illness.

The interviews took approximately one hour and were conducted in a private office at the cystic fibrosis clinic or in the family home. In 9 of the interviews only the mother was present and in the other 2 both parents were present. All interviews were taped and the tape recordings
were transcribed verbatim with the resultant data being summarized into categories. Descriptive statistics were used to analyze the data.

All 11 families interviewed described difficulties in one or more areas of communicating about the illness but only one parent out of 11 said she needed guidance in how to talk about the illness with her children. Most parents did not seem to recognize the importance of their children having a thorough understanding of cystic fibrosis or the importance of their being able to talk openly about their feelings related to the illness experience.

Parents varied in the amount of information they gave their children about the illness, but the majority said they had not specifically explained the facts; these had just evolved over the years through living with it. The one difficulty which all parents admitted to was not knowing how or what to tell their children about the prognosis. Only one parent had mentioned life expectancy to his child. Most others reported they lived in fear of their child finding out. When asked if they thought their children were getting information about the illness from sources other than themselves, the majority of parents responded affirmatively, although they admitted to trying to screen the information
reaching their children.

Most parents appeared unaware of age-appropriate explanations and said they gave all their children the same explanation, regardless of age. The majority of parents did not repeat explanations about the illness and only 2 parents checked their children's understanding of cystic fibrosis.

Parents, with one exception, said they were comfortable talking about the illness; but on further questioning, most admitted to being uncomfortable talking about certain aspects of the illness or at certain times during the course of the illness, such as the first few months after diagnosis or when the child was sick.

Four parents said their children asked few or no questions about the illness. The questions asked by children in the other families seemed to fall into 2 main categories: the why questions of the 3 to 5 year olds and the more searching questions of the 11 to 13 year olds. Some parents mentioned that their children accepted it much more matter of factly when younger but when they got older and became more aware, they had a more difficult time accepting it.

In the area of feelings, 6 of the 11 parents interviewed said they did not talk about their own feelings because they had no one to talk to. Some parents
mentioned that their own extended family and friends made it clear that they did not want to talk to them about it. The same number of parents did not talk to their ill child about his feelings. Of the 5 parents who did talk to their ill child about his feelings, the most frequently mentioned feelings were anger, depression, fear and embarrassment.

The majority of parents said they thought their well children were not adversely affected by having a sibling with a chronic illness. Of the 5 parents who did think their well children were affected, none of these talked to their children about their feelings on having a chronically ill brother or sister. A minority of parents, 3 of the 11, expected their well children to take some responsibility in caring for the ill child.

Of the 11 parents interviewed only one had been given guidance specifically related to discussing cystic fibrosis with her children. None had received guidance in age-appropriate explanations. When asked what had been most helpful in discussing the illness, the parents most frequently mentioned other parents, the parents' own philosophy and the information they received about cystic fibrosis.

When asked what would have been helpful, parents said; someone to talk to about their own feelings, teachers
being better educated about cystic fibrosis and more support at the time of their child's diagnosis.

In conclusion, based on the findings of this study:

1. Most parents in this study do not perceive the importance of their children having a thorough understanding of cystic fibrosis or the importance of their having opportunities to express their feelings about either having the disease or about living with a sibling who has the disease.

2. Most parents in this study do not communicate effectively with their children about cystic fibrosis and its effect on the family. Areas where guidance is needed are: giving children adequate and age-appropriate information; checking the children's understanding of the illness periodically for any misperceptions and encouraging their children to express their feelings about living with cystic fibrosis.

3. Parents need support at the time of diagnosis and in the months following to help them reach an understanding of cystic fibrosis and its effect on their lives and the lives of their children.

**Implications**

Although the design of this study is such that the findings can only be considered tentative, they strongly
suggest that parents do need guidance in communicating about their child's chronic illness within the family. This holds implications for nursing practice, education and research.

Nursing Practice

This study points to the importance of assessment in caring for the chronically ill child and his family, especially in the area of the family's communication about the illness.

The time of initial diagnosis was identified as a time when families began having problems communicating about the illness. This was due to their not receiving enough information about the illness or not being able to retain all they did receive. While it is usually the physician's role to inform parents initially of their child's illness, nurses are often in contact with the family on a more ongoing basis and are in a position to assess how they are coping. There should be a follow-up of the initial information session at regularly scheduled times so concerns and questions which the family has can be resolved.

During these regularly scheduled conferences the families' perceptions of the experience of having a chronically ill child should be explored. Also, the support systems they have should be identified and discussed. What impact
has the diagnosis had on extended family members? While it is very important that both husband and wife attend these conferences, it might also be important to include significant others in the extended family who will have an influence on family coping. In this way, it is more likely that all family members receive the same message and have the same opportunities to explore the meaning the illness has for them. This could be an important factor in opening up communication within the family.

Since this study suggests that the meaning of the illness changes as the child enters different stages of development, health professionals should provide ongoing assessment to identify any problems in the child's and/or family's adjustment to the illness. This assessment could be twice a year and/or at potential crisis points along the way, such as when the child with cystic fibrosis or his siblings enters school, when the ill child is hospitalized, etc.

Anticipatory teaching is a very important aspect of working with families of chronically ill children. It can provide parents with the tools they need to communicate effectively with their children. For example, the nurse can introduce the normal feelings that siblings may have and suggest ways that parents might deal with them or she may explore with parents the kinds of questions the children may
ask and how they might answer them. Although this can be done on a one to one basis with parents, a parent education group in which these issues are raised and discussed could be very useful. The nurse could incorporate the information she wants to share with examples parents bring to the group. This could provide a meaningful learning experience for all involved.

In addition to anticipatory teaching, parents need a chance to express their feelings on an ongoing basis since the child's illness places heavy demands on their energy and time. This needs to be recognized and support given to their efforts. Specific times should be set for this purpose so the focus is taken off the sick child and put on them. A possible time for this may be when they bring their child to clinic since they usually spend a couple of hours sitting in the waiting room while the child has his lab tests, x-rays, etc. The present study showed that parents freely expressed their feelings when they were given the opportunity to do so.

Nursing Education

Students in all nursing programs should receive instruction in knowledge and skills related to chronic illness and its effect on the entire family. The content should include a variety of chronic illnesses and their effect on
different family members at different stages of their lives. The commonalities as well as the differences should be explored. Emphasis should be placed on how these families cope - what constitutes effective coping or ineffective coping in relation to roles, communication, interaction, etc. Discussion of the kinds of support these families need would be important. The content would be based on a variety of theories including communication, coping, development, family interaction and change theories. Students would be given opportunities to work closely with a family having a chronically ill member over an extended period of time to develop skill in ongoing assessment and intervention. Since students would be working with a variety of families, a discussion group/seminar would be an effective method of teaching since all could share their experiences and identify the similarities and differences of each family's experiences.

The preparation of a series of slide-tape shows on families of children with cystic fibrosis would be a good teaching tool not only for health professionals working with these families but also for the families themselves. It would include one on assessment of families at various stages of the child's development including individual family members' concerns about the illness experience. This would
bring out how the illness poses different social, emotional and intellectual problems at different stages of the child's development. There could be one on how the family talks about cystic fibrosis within the family and difficulties they have, using questions similar to the ones for this study. Another slide-tape could be prepared on anticipatory teaching including such things as normal sibling reactions and how to handle them, how to encourage children to share their feelings, etc. In all of these tapes actual families of children with cystic fibrosis would be interviewed by the nurse.

These tapes could be made available to the cystic fibrosis clinic and parents could watch them during their waiting times at the clinic. They could also be made available to continuing education departments within the hospital and used as part of their orientation program for staff in pediatrics.

Nursing Research

This study should be repeated using a much larger sample to determine if the results are applicable to a majority of families with a child with cystic fibrosis. It would also be useful to include a test of the ill child and his/her siblings' knowledge of the facts of the illness.
as, what cystic fibrosis is, what causes it, how long will they have it, etc. This would validate or invalidate the parents' statements that the child understands his illness. It would also be useful to do the same study using different populations such as families of children with diabetes, epilepsy, cancer, hemophilia. Are there similarities in the way parents communicate about the illness with their children? What are the differences? What factors account for these differences? What about families with handicapped children - are there communication problems in relation to the handicap? Is there a difference if the handicap is congenital or acquired in terms of communicating about it?

Since many areas of potential difficulty in communicating were exposed in this study, the development of a reliable and valid tool for assessing communication would be useful. Once the tool is developed it could be used on a variety of families with a chronically ill child.

The whole area of the effect of the chronically ill child on the siblings' needs to be explored. A study could be done in which siblings' perceptions, concerns, feelings are explored using a semi-structured interview and/or drawings depending on the age of the child.

**Recommendations for Further Study**

On the basis of the findings and implications of this study, it is recommended that:
1. An assessment tool be developed and validated to assess communication patterns in families with a chronically ill child.

2. This study be repeated using a larger sample and including a test of the children's knowledge of the facts of the illness.

3. This study be repeated using different populations such as families of children with diabetes, epilepsy, cancer, hemophilia, physical handicap.

4. Research be conducted on the siblings of children with cystic fibrosis, exploring their perceptions, concerns and feelings.
BIBLIOGRAPHY


Kulczycki, L. et al. "Psychological Factors Relative to Management of Patients with Cystic Fibrosis."


APPENDIX A

Letter of Consent

Dear ____________:

I am a registered nurse in the masters program at the University of British Columbia.

I am doing a study on how parents of children with cystic fibrosis talk about the disease within the family. The purpose of the study is to obtain a better understanding of how nurses can be helpful to these families.

I would like to meet with you and your husband/wife to discuss how you talk about cystic fibrosis in your family, and to find out what support you have received from health professionals in talking about the disease. This discussion would take approximately one hour at a time convenient to your family.

The anonymity of all participants will be maintained. Initials rather than family names will be used and although the interview will be taped, the recording will be available only to myself and my thesis committee. The tape will be erased within three months of the interview.

If you agree to participate in the study, you are still free to withdraw at any time without jeopardizing your child's treatment.

If you are willing to participate in the study I will make an appointment to visit you at your home. If you have any questions about the study in the near future or after the results are available please call me at 266-6592.

If you consent to take part in this study as described, please sign this letter in the space provided. Thank you.

Sincerely,

Connie Canam R.N., B.N.

Name ______________________

Date _______________________

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APPENDIX B

INTERVIEW SCHEDULE

Demographic Data: Initials
Number of children and ages
Age of child with cystic fibrosis
Length of time since diagnosis

Introduction

Families who have a child with cystic fibrosis often have a difficult time explaining and discussing the illness with their children. Children may ask questions which are hard to answer and parents often avoid the question because they don't have the answer.

I would like to spend the next hour hearing what difficulties you may have experienced in talking about the illness with your children, what has been helpful to you in talking about the illness and what guidance you have received from health professionals in this area.

Body of the Interview

1. Let's begin by having you briefly explain what cystic fibrosis is.
2. (a) Have you explained __________________'s illness to him? To your other children? If not, why?

(b) When?

(c) What have you said?

(d) Who initiated the discussion?

(e) Did you give the same explanation to all of the children?

(f) What was your reason for this?

(g) Have you repeated the explanation?

(h) Do you feel you have told them enough?

(i) If not, what else should be said?

(j) Do you mention the name of the diagnosis? If not, why not?

(k) If your child must be hospitalized, what do you tell him? What do you tell the other children?

(l) What questions do they ask?

(m) What do you tell them about going to the clinic?

3. Have you ever checked with your children about their understanding of the disease? For example, "John, if one of your friends asked you what cystic fibrosis is, what would you say?"

4. (a) Are you uncomfortable talking about the illness?

(b) Can you pinpoint the reason for this?
5. (a) Have your children, including _________ (name of child with cystic fibrosis) ever asked questions about the disease?

(b) What kinds of questions have they asked?

(c) How often?

(d) How have you answered these questions?

(e) If they don't ask questions, do they comment on it at all?

(f) If not, what do you think the reason is for this?

6. (a) Do you encourage their questions?

(b) How?

(c) If not, why?

7. (a) What kinds of things do you and your spouse talk about in relation to your child's illness?

(b) Is there any one issue which dominates the conversation?

(c) Do you discuss the illness when any of the children are around?

Parents and children often have feelings about living with a child who has a chronic illness; such as sadness, frustrations, anger, etc. The ill child, too, has many anxieties and feelings about his illness. People frequently have difficulty expressing their feelings. They may feel they are the only ones who have felt a particular way and that
others wouldn't understand or accept their feelings.

8. (a) Do you talk about your feelings with anyone? If not, why?

(b) When you are feeling tired and cranky, do you tell your children this? If not, why?

9. (a) Do you ever talk to _______ about his feelings?

(b) What do you say?

(c) If not, why?

10. (a) How do you think your well children feel when you must devote so much of your time to _______?

(b) Do you talk about this with them?

(c) What do you say?

(d) If not, why?

11. When your well children misbehave to get your attention, what do you say to them?

12. When your well children react in angry, resentful ways toward ________, what do you say to them?

Nurses and doctors may not always realize the difficulties of talking about the illness with your children.

13. (a) Have you ever been given guidance from health professionals - doctors, nurses, etc. about discussing cystic fibrosis with
your children?

(b) From whom?

(c) What kind of guidance?

(d) Was it helpful?

(e) In what way?

14. (a) Has anyone talked to you about explaining the disease in different ways depending on the age of your child?

(b) What were you told?

15. (a) Who or what has been most helpful in helping you discuss your child's illness with him and your well children?

(b) In what ways were they helpful?

(c) What else would have been helpful?

Termination of the Interview

Summarize briefly what has been discussed. Express appreciation for their efforts. Tell them they may have a copy of the overall results if they wish.