EFFECTS OF CYSTIC FIBROSIS ON FAMILIES

by

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INTRODUCTION

Cystic fibrosis (C/F) is a hereditary disease of children which was first identified as a distinct disease in 1938. Before that time, most children afflicted with it died in infancy from malnutrition or bronchopneumonia and the underlying disease was unsuspected.

Although the basic genetic defect has not yet been identified, a diagnostic test based on the salt content of sweat was developed in 1954, and the treatment regimen for afflicted children has been greatly improved since that time.

Cystic fibrosis is a public health problem of increasing importance. At the present time, it has the highest incidence and mortality rate of any of the hereditary diseases of children. A pilot study of three New England states, made by the Children's Bureau (U. S., Congress, 1964), estimated the incidence of C/F at a minimum of one per 2,300 live births. In the pilot study area, the annual number of recognized cases increased by fifty-seven per cent from 1952 to 1959, and the annual caseload of the disease among children under eighteen rose from twelve per 100,000 to twenty-two per 100,000. During this seven year period, the number of patients doubled in the age group under five, tripled in the age group from five to nine, and quadrupled in the group ten years and older. These figures show that early diagnosis and improved treatment are allowing children with C/F to live longer.

The White House Conference on Children and Youth (1960) identified some social problems resulting from the advancement of medicine in relation to handicapped children as: (1) the reduction of mortality, but not yet the reduction of residual defects, (2) the impatience of people with long-term treatment, (3) the increase in specialized skill and equipment needed for rehabilitation of handicapped children, and (4) the tendency to reduce the child's hospital stay which increases the responsibility of the family for treatment.

The increasing number of surviving children with C/F presents many new problems to families and communities. The family, concerned for the life of the child, is responsible for a long-term program of daily care which is expensive and time-consuming, and with which they may not be able to cope.

Anderson (1960) recognized the strain that C/F places on families as "great, often devastating", and grouped pressures into three categories; those directly concerned with the care of the patient, the financial stresses, and the problems presented by the disease's hereditary nature.

Parents of C/F children have responded by organizing the National Cystic Fibrosis Research Foundation. The educational program of the foundation has increased public awareness of the disease. As a result, effective action is being taken in some areas.

At the present time, the National Institute of Health is sponsoring and coordinating research projects to determine the basic genetic defect, to further improve therapy, and to obtain national incidence and prevalence rates for the disease. Clinics have been established by the foundation at thirty-four hospitals across the country to provide specialized care for patients and to conduct research. Thirty-three states now include C/F in the group of diseases supported by Crippled Children's funds.

The writer became concerned with C/F when her daughter became a patient at the clinic in Kansas City. An appreciation of what has been accomplished, an awareness of problems families still face, and an interest in improving family life led to this study.

Upon investigation, it was found that very little research had been done on the effects of C/F on the family. Turk (1954), in a study of twenty-five families at the Bethesda, Maryland C/F clinic, found that those families were experiencing difficulties in meeting family needs and in maintaining normal family relationships.

Objectives of the Study

Family counseling services are provided at most C/F clinics. The Kansas City clinic has been established a relatively short time, and does not as yet provide such services. With the interest and cooperation of Dr. Joseph Kanarek of the C/F clinic in Kansas City, and the Kansas City chapter of the National Cystic Fibrosis Research Foundation, this study was undertaken (1) to investigate further the ways that families of C/F children have adapted to the home treatment needs of the ill child, (2) to identify the causes of stress and its effects on the functions of the family, and (3) to determine the sources of help utilized by families. The results of the study will be made available to the board of the foundation chapter and to Dr. Kanarek. It is hoped that counseling can be made available to families through the clinic and that the study will be useful in determining the kind and degree of help that will enable the increasing number of C/F families to successfully care for their children.

CHAPTER I

REVIEW OF LITERATURE

The C/F Child as a Family Crisis

Cystic fibrosis of the pancreas has been described medically (Landauer, 1963, p. 1) as:

> a generalized, hereditary disorder of children, adolescents, and young adults in which there is widespread dysfunction of exocrine glands. In the fully manifested cases there is chronic pulmonary disease, pancreatic enzyme deficiency, abnormally high sweat electrolytes and, at times, cirrhosis of the liver. However, the disorder is characterized by many variations in the degree of involvement of organs and glandular systems usually affected, leading to many variations in the clinical picture.

Cystic fibrosis therefore is not solely a disease of the pancreas but one in which many exocrine glands are affected. It may easily be confused with a number of other respiratory and gastrointestinal disturbances. Diagnosis is based on laboratory evidence of abnormally elevated sweat electrolyte levels and/or pancreatic insufficiency. It was further stated (Landauer, p. 65) that:

> As the disease has considerable variation in severity of clinical manifestations, so must prognosis vary, from good to bad. The future of the individual patient is unpredictable, especially in infancy. In general, the outlook depends almost entirely on the course of the pulmonary lesion...on the degree of damage that exists at the time the disease is diagnosed and adequate therapy is initiated.

Schwachman (1958) studied 105 patients who had been under treatment for C/F for a minimum of five years. A summary of their clinical status showed that 47 improved, 27 were the same, 21 were worse, and 10 had died.

He concluded that the widely held belief that C/F inevitably a fatal disease in infancy or early childhood is not substantiated by experience.

Nudelman, et al. (1960) studied 54 patients at four-month intervals for three and one-half years. Of these patients, 57.6 per cent showed improvement, 23.5 per cent showed mild improvement, 11.7 per cent made no change, 3.5 per cent deteriorated, and 3.5 per cent died.

A five-year clinical evaluation of 96 patients followed for periods ranging from eighteen to sixty months (Doershuk, et al., 1964) revealed that 82 per cent showed improvement, 11 per cent remained the same, 4 per cent showed progression of the disease, and 3 per cent had died. None of the deaths occurred before five years of age.

The growth patterns of 50 children with C/F were studied by Sproul and Huang (1964). Significant retardation of physical growth was observed in all age periods and was most pronounced in the preadolescent and adolescent age groups. A significant correlation was shown between growth retardation and the pulmonary involvement, but no correlation was found between retardation of growth and the degree of pancreatic insufficiency.

Recent evidence has shown that the diagnosis of C/F carries with it a serious but far from hopeless prognosis. Even so, a syllabus for physicians (Landauer, 1963) advised that: "the establishment of a diagnosis of C/F is a severe blow to any family, ... and it is therefore urged that the diagnosis be made only on the accumulation of sound clinical and laboratory evidence."

Almost any unexpected event for which a family is unprepared may be interpreted as a crisis (Cavan, 1963). The threatened loss or disability of a child is a crisis for any family. Winch (1963) stated: "The child can be viewed as a representation of immortality through constituting the link between the parent and posterity, and the fact that the child is one's own flesh and blood makes an offspring, generally speaking, the most important thing a parent has."

Hill (1949) defined crisis as "those situations which create a sense of sharpened insecurity or which block the usual patterns of action and call for new ones." He identified three variables which determine whether a given event becomes a crisis for any given family: (1) the hardships of the situation or event itself; (2) the resources of the family, its role structure, flexibility, and previous history with crisis; and (3) the definition the family makes of the event.

In discussing the impact of the handicapped child on the family, Cohen (1962) stated that: "Grief and anger at the blow life has dealt them are almost universal reactions." She described a series of adjustment stages which parents need to work through before they can reach the point of accepting the child's handicap as (1) a period of grief, (2) acknowledging and learning to handle their anger, (3) dealing with the anxieties aroused by the impact of the child's handicap on their usual adaptive patterns, and (4) making certain adjustments in their way of life that will affect not only the handicapped child but the total family unit.

According to King (1963), the emotional intensity of relationships in the small family allows little room for absorbing shock, and most families find it difficult to maintain an optimum balance between the supportive and dependent aspects of sickness on the one hand and the disciplinary aspects of treatment on the other. He further suggested that the relationship between the ill person and the family be analyzed through the allocation and meaning of roles in the areas of work, authority or decision-making, and emotional support or affection.

Freidson (1963) stated: "What people believe, know, and do about illness is necessary and useful as a way of understanding the social and cultural elements they bring to the process of being sick." He suggested the organization of responses to illness over a period of time, and by role analysis.

The effect of the mother's conception of her retarded child's capabilities on family integration was studied by Farber (1959). He found that the mother's rating of the degree of the child's dependence was not related to the marital integration of the parents, but was related to the degree of role tension of the normal siblings.

Wershow (1963), in a study of families of children with muscular dystrophy, found that, beyond the beginning stages, people do not in general react to chronic illness with overwhelming depression, and suggested further research be alert to the possibilities of positive as well as negative responses to illness.

C/F and Family Size

The hereditary character of C/F has implications for families. The basic defect is genetically transmitted as a recessive trait. It has been estimated (Landauer, 1963) that as many as two to five per cent of the general population may be carriers of the C/F gene. The disease has been found to occur approximately equally in all groups of the Caucasian race, very infrequently in Orientals, and rarely in Negroes. It occurs equally in both sexes. Individuals carrying the gene usually show no symptoms, but may transmit the disease to their offspring if they marry another carrier. When both parents carry the C/F gene, the probability is one in four that a child will have C/F, two in four that he will be a carrier, and one in four that he will be normal. A family may have a number of children before the symptoms appear or the disease is diagnosed.

In Turk's (1964) study of 25 families, five families had two C/F children, one family had three, and one family, four.

Schwachman (1957) stated that upon diagnosis of C/F, parents are made aware of the expense of treating the child and of the 25 per cent chance that subsequent children will have C/F. He recommended that readjustments of the future plans for a family be considered by parents.

A basic function of the family in society is child-bearing (Winch, 1963). Anderson (1957) stated that "repeated production of abnormal children by a particular couple poses problems for society as well as for them," and that, "at the present time, society recognizes a duty to help care for such children, but no duty or privilege to help in their prevention."

Turk (1964) found that the question of having another child was a significant area of breakdown in communication between parents.

Treatment for C/F and Family Adjustment

Mathews _et al_. (1964) described a comprehensive therapeutic program for children with C/F. The treatment consists of therapy aimed at minimizing progression of the disease.

The secretion of abnormal mucous in the lungs results in bronchial obstruction and impairment of breathing. Methods of therapy include medicated aerosol treatments, mist tents, home humidifiers, postural drainage, chest vibration, breathing exercises, and intermittent positive pressure breathing treatments. If secretions accumulate in the lungs, infection results. Antibiotic therapy is used for both prevention and treatment.

The pancreatic insufficiency results in impaired digestion and therefore malnutrition. It is treated by restricting the diet to high protein, low fat foods, increasing vitamin dosage, and prescribing a pancreatin preparation to be taken with food to aid in digestion.

Children with C/F lose excessive amounts of sodium and chlorine in their sweat. When sweating is profuse as in hot weather or during physical exertion, salt is added to the diet. Air conditioning may be recommended.

Hospitalization is necessary for such complications as Meconium Ileus, cirrhosis of the liver, thoracic surgery, or heart failure. Because of the great variation in the disease and the necessity of adapting treatment to the individual patient, the importance of frequent observation, critical evaluation, and close supervision by a physician experienced in the treatment of the disease has been emphasized (Landauer, 1963).

Mathews _et al_. (1964, p. 572-3), in discussing the treatment of 167 patients stated:

> Almost all of the patients attend school regularly and engage in normal activities insofar as their condition permits. The psychologic attitudes and problems of the patients are closely followed, and every effort is made to help the individual adjust to life with a chronic disease. Information and instruction are provided as the child becomes capable of accepting and understanding the material . . . . Every effort is made to keep both the patient and his family enthusiastic, hopeful, and secure in their approach to life. Our success with this program permits us to share this attitude with them.

Medication and physical therapy were prescribed to be carried out at home on an out-patient basis. Mathews (1964) found that a period of hospitalization was effective for initiating treatment; both for helping the child become accustomed to it, and for instructing the parents. Schwachman (1958) emphasized that energetic therapy in the home not only improves the patient's condition, but also results in an economic advantage since hospitalizations are avoided, and stated that the effectiveness of any long-range therapeutic program depends on the cooperation of parents.

The cost of treatment for a C/F child has been estimated by Anderson (1960) as $1,000 to $1,500 per year, and by the National Cystic Fibrosis Research Foundation (1963) as $1,200 per year. The annual cost was not given in Turk's study (1964); however, even though those families were receiving hospital care and medication free of charge, finances were found to be one of the most stressful areas in the relationship between parents.

No estimate of the time required for daily care has been found, possibly because of the great variations in the disease, and consequently in the treatment required. Turk (1964) found that parents felt deprived of time and energy to engage in leisure-time activities for the family, time to be alone with spouse, time and energy to engage in adult activities, and time for self.

Rogers (1964) defined the family as "a semi-closed system of interacting personalities which is composed of interrelated positions and roles defined by the society of which it is a part as unique to that system." He further stated that little attempt has been made to analyze the family as it exists with unexpected death, disability, abnormality of either a physical or mental kind, adoption of children, remarriage, or the occurrence of separation and divorce.

Mandelbaum and Wheeler (1960), in discussing the meaning of a defective child to parents, stated that the focus of concern has been on the child and that little professional consideration had been given to the problems of parents.

Mabry (1964) and Richardson (1945) both pointed out the difficulties in coordinating the goals of medicine with those of the family, and expressed concern for developing a more comprehensive approach to patients and their families. Mabry described points of revelance between medicine and six family functions; physical well-being and health maintenance, biological reproduction, emotional development, socialization, organization of statutes and roles, and relations between the family and the community. He stated that family members may have little concept of chronic illness; they may need to learn techniques of care and rearrange the home in order to carry out a treatment regimen. He further stated that families vary in their capacity to adapt to illness, and consequently, there is often inadequate attention to treatment.

Gesell (Michael-Smith, 1957, p. viii) stated that:

> In addition to medical and other professional skills, the management of childhood handicaps usually involves educational measures for child and parent. The child, so far as possible, must learn to live with his handicap and to meet its challenge. In essence, that is also the task of the parent. . . . .
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> . . . .
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> The scope of management . . . embraces not only the diagnosis and specialized treatment of specific disability, but extends to the total network of interpersonal relationships in which the child will live and have his being.

Rusk (1957) stated that the sheer burden for the family in financial and psychological terms is related to the degree to which normal living patterns are destroyed, but that the physical, emotional, and financial strains are bound to have their effect in any situation. He noted the importance of realistic adaptation on the part of the family. However, Wershow (1963) found that when reality problems of the illness were solved, the families of children with muscular dystrophy were able to adjust psychologically.

Young (1960) stated: "The most important single need for the modern family is that of adaptability . . . in order to survive, it must develop new resources to meet recurrent crises." Hill (1949) stated that an initial crisis and period of disorganization are followed by recovery and reorganization, and that the level of reorganization represents the ability of the family to adapt or adjust to the new situation.

Voiland (1962) suggested examining the attitudes and behavior of family members shown in meeting their responsibilities in three areas; (1) child-rearing, (2) the marital relationship, and (3) financial management as a means of identifying problems.

The effects of a mentally retarded child on family integration were studied by Farber (1959) as arrest in the family life cycle causing lack of concensus of its members as to domestic values and role tension in the interpersonal relations between family members. He found that the marriages of parents with mentally retarded boys were more often adversely affected than marriages of parents with retarded girls, and that normal sisters were more adversely affected than normal brothers.

Winch (1963) stated that maintenance of economic dependents is becoming increasingly difficult for families in our economy and that in consequence, the care of certain categories of dependents has been passing from the family to private and public social agencies, particularly at the lower income levels. This has resulted in uncertainty as to the rights and obligations of the family in seeking financial help.

Pollack (1964) said that pathology of the family can be recognized from symptoms just as physical illness of a person is diagnosed. He described insufficient communication and partial breakdown in cooperation as the most significant symptoms. Communication was defined by Burgess (1953) as the mechanism through which family members exchange ideas, attitudes, and values in order to modify each other's behavior. Meissner (1964) found that in normally functioning families, the role structure is continually changing in terms of the needs and expectations of family members, but in a disturbed family, role structure remains the same despite other changes.

Turk (1964) found significant problems in communication between members of C/F families, not only between parents but between parents and the ill child and between parents and the other children.

The writers tend to agree that the family is a dynamic or constantly changing organization and that the ability of family members to make changes in response to changed conditions depends on their ability to communicate with each other.

CHAPTER II

PROCEDURE

The need for family counseling services and for a study of C/F families was discussed with Dr. Kanarek. He was enthusiastic and made arrangements for the investigator to talk with Mrs. Mullaly, Executive Secretary of the Kansas City chapter of the National Cystic Fibrosis Research Foundation. The board of the foundation chapter approved the study and released its lists of members and clinic patients for the investigator's use. The lists included 23 families using clinic facilities in January, 1965, and about 165 chapter members who had worked on or contributed to fund drives. Mrs. Mullaly, who had contacts with many of these persons, indicated those families whom she thought had a C/F child. The membership list was further limited to families living in Kansas and Missouri.

Mothers were chosen for the subjects because it was assumed that they were primarily responsible for the child's daily care and because time and travel limitations precluded contacts with all family members. A questionnaire and interview schedule were developed and pre-tested with three mothers. After some rewording, the questionnaire was reviewed and approved by Dr. Kanarek.

Questionnaires (Appendix, p.53) were sent to 23 mothers of clinic patients and 92 other chapter members who it was thought might have a C/F child in an effort to locate as many families of C/F children as possible in this area. Follow-up letters were sent after ten days to 13 clinic mothers, and post cards after another ten days to four clinic mothers who had not yet returned the questionnaire. No follow-up was made of the foundation members. Questionnaires were returned by 22 of the 23 clinic mothers and by 41 of the 92 foundation members; a total of 63. Twenty-one of the returned questionnaires were not used in the study for the following reasons: in nine families the C/F child had died, in seven families the C/F diagnosis had not yet been definitely established, four families had never had a C/F child, and in one family, an adult had C/F.

The 42 questionnaires used in the study represented families with one or more C/F children living at home in February-March, 1965. Twenty of the families were using clinic facilities, and twenty-two families, located through the foundation membership list, were using private medical services.

The purpose of the questionnaire was to collect factual information about each family and how it was meeting the crisis of a C/F child. The questionnaire consisted of a face sheet, seven multiple-choice questions and four free-response questions which were adapted from the questionnaire developed by Turk (1964).

It was found that the 42 families had a total of 127 children; 49 C/F children and 78 other children. The mean family size was three children per family, although the range was from one to nine children. Twenty-six of the families had one C/F child, five families had 2 C/F children and one family had 3 C/F children.

Fifteen of the 42 mothers were interviewed to gather data on their attitudes and plans for the future. The interview schedule (Appendix, p. 59) which was pre-tested at the same time as the questionnaire, consisted of seven questions related to treatment, seven concerned with family relationships, and four related to finances. The mothers interviewed were those who lived in the Topeka and Kansas City areas which were within traveling distance for the investigator. Appointments were made by telephone, and the interviews were conducted in the mother's homes. Of the fifteen interview families, six were using clinic facilities and nine had private physicians. The time for the interview ranged from thirty minutes to over an hour. All of the fifteen mothers contacted agreed to be interviewed and many expressed appreciation for the opportunity to help with the study.

The data obtained from questionnaires were first summarized for the entire group. The questionnaires were then divided on the basis of the median length of time C/F had been diagnosed in the family (21 in the three years or less group and 21 in the more than three years group) and on the basis of the mother's definition of the C/F child's condition (22 in the good group and 19 in the poor group). Differences were analyzed statistically by the chi-square method. Upon the recommendation of Dr. Fryer, the significance level of .10, as well as the levels of .05 and .01, was identified due to the small size of the groups.

CHAPTER III

DATA

Characteristics of Questionnaire Respondents

Age of C/F Children

The 49 C/F children in the 42 families who responded to the questionnaire ranged in age from under one year to 17 years, with the mean age 6.87 years, and the median age 6 years (Table 16, Appendix, p. 52). Eighteen children were under five; 24 were five to twelve, and seven were 13 to 17 years of age.

Length of Diagnosis

The length of time since C/F had first been diagnosed in the family ranged from less than one year to 16 years, with the mean 5.33 years, and the median 3 years (Table 17, Appendix, p. 52). The condition had been diagnosed for three years or less in half of the families.

Mother's Definition of Condition

Twenty-two mothers described their C/F child's condition as good or nearly normal; nineteen mothers described it as fair, poor, or severe.

Treatment of C/F Children

When asked to describe the daily treatment and care of their C/F child, 38 mothers listed diet and medicines, 25 stated that the child slept in a mist-tent, and 23 mentioned inhalation therapy and postural drainage.

In 25 of the 42 families, a C/F child had been hospitalized at some time during 1964. The cost of medicine and equipment for home treatment (excluding hospitalization expenses) during 1964 ranged from $175 to $3,600 per family; the mean was $964.85.

Parents

The 42 mothers ranged in age from 22 to 49; the mean age was 33 years. Thirty-nine mothers had been married from four to 27 years; the mean was 12.2 years. One mother was separated from her husband and two mothers had remarried. Of the 41 husbands present in the homes, two were step-fathers of the C/F children. The ages of the husbands ranged from 24 to 51 years with the mean, 35.2 years.

Family Size

The families varied in size from one to nine children; 4 families had one child, 14 families had two children, 12 families had three, 6 families had four, 4 families had five children, one had six, and one had nine. The mean family size was three children. Four families had previously lost one C/F child.

Siblings of C/F Children

Of the 78 siblings of C/F children, 46 were older and 32 were younger. Eight families had a C/F child or children only with no well siblings; 34 families had at least one well sibling. Fourteen families had one or more children at least one year after C/F had been diagnosed in the family.

Family Income

Eight mothers checked the total yearly family income as less than $5,000, 32 as between $5,000 and $10,000 and one as over $10,000. Nine of the mothers were employed full-time and four, part-time. The mother who was separated from her husband worked full-time as a waitress and had an income under $5,000.

Grandparents of C/F Children

In seventeen of the families, at least one of the child's grandparents lived within five miles, and 13 other families had a grandparent within 100 miles; a total of 30. In the remaining 12 families the grandparents either lived farther away or were deceased.

Questionnaire Responses

Persons Who Helped Mothers with C/F Child's Care

Husbands were the most frequent source of help with the child's daily treatment and care. Table 1 shows that 29 of the 40 mothers who reported said that their husbands helped occasionally or often. A grandparent or other relative helped occasionally or often in 11 families. Help was seldom obtained outside the family. Some mothers mentioned that the C/F child needed very little additional care.

Persons with Whom Mothers Discussed Child's Illness

The main source of emotional support for the mothers was their husbands; 41 of the 42 mothers discussed the child's illness occasionally or often with their husbands (Table 2). Thirty-five mothers talked with their own parents and relatives, and 28 mothers talked with their husband's parents and relatives about the illness. Since only 30 families had one or more parents living within 100 miles, the responses indicated that most

TABLE 1

PERSONS WHO HELPED MOTHERS WITH C/F CHILD'S CARE[1]

Person	Frequency of Help		
	Seldom or Never	Occasionally	Often
Husband	11	12	17
One of C/F child's siblings	33	6	1
Grandparent or relative	28	8	3
Neighbor or friend	36	3	1
Volunteer or community nurse	39	1	0
Paid helper or nurse	38	1	1

[1] 40 mothers reporting.

TABLE 2

PERSONS WITH WHOM MOTHERS DISCUSSED C/F CHILD'S ILLNESS[1]

Person	Frequency of Discussion		
	Seldom or Never	Occasionally	Often
Husband	1	11	30
Mother's parents and relatives	7	21	14
Husband's parents and relatives	14	20	8
Friends, neighbors	13	21	8
C/F child's teacher	25	14	3
Clergyman	24	13	5
Public health or visiting nurse	35	7	0
Counselor	40	2	0

[1] 42 mothers reporting.

mothers did talk with parents when they were available. Friends and neighbors were also important sources of support. However, few mothers ever discussed their child's illness with the professional persons listed; teacher, clergyman, public health or visiting nurse, or a counselor.

Changes in Family Life Due To Child's Illness

Table 3 shows that the changes which families made most frequently were giving up vacations or trips and savings. Other activities outside the home such as baby-sitters, eating out, visits to friends and relatives, and church and community events were given up some or all of the time by over half of the families. Nearly half of the families stated that they had not changed having the children's friends in; over half had not changed hobbies or lessons for other children in the family. The changes may have been due to financial limitations, to the need to be at home to care for the child, or to the desire to protect the child from infection. The areas of least change involved the children of the family. However, 12 of the 42 families stated that they had given up the house they were living in; this change is an indication of severe financial strain.

Each mother was also asked to indicate changes in adult activities which she and her husband had made due only to a lack of time and energy (Table 4). Evenings out as a couple and church, clubs, and hobbies were given up most frequently; sexual relations of marriage and doing things with siblings, least frequently.

The families in the study were divided into two groups according to the median length of time that C/F had been diagnosed in the family; three years. When changes in family life in the two groups were compared by chi-square analysis (Table 5), significant differences were found in several

TABLE 3

CHANGES IN FAMILY LIFE DUE TO CHILD'S ILLNESS[1]

Things Family Had Given Up:	Yes	Sometimes	No
Baby-sitters	13	12	17
Eating out	15	10	17
Vacations or trips	20	6	16
Visits to friends or relatives	9	15	18
Church or community activities	9	18	15
Having children's friends in	7	15	20
Hobbies or lessons for siblings	8	8	26
House they were living in	12	0	30
Savings or insurance plans	19	5	18

[1] 42 mothers reporting.

TABLE 4

CHANGES IN COUPLE ACTIVITIES DUE TO CHILD'S ILLNESS[1]

Activities Couple Had Given Up:	Yes	Sometimes	No
Evenings out as a couple	19	11	8
Planning family activities	13	13	12
Sexual relations of marriage	5	14	18
Entertaining adults	14	12	12
Doing things with siblings	12	7	19
Church, clubs, hobbies	18	11	9

[1] 38 mothers reporting.

TABLE 5

CHANGES FAMILY HAD MADE AS RELATED TO LENGTH OF TIME SINCE C/F WAS DIAGNOSED IN FAMILY

	Number of Yes Answers		
Things Family Had Given Up:	Diagnosed 3 yrs or Less (N = 21)	Diagnosed More Than 3 yrs (N = 21)	Chi-square
Baby-sitters	16	9	5.50*
Eating out	18	8	10.95**
Vacations or trips	14	12	.66
Visits to friends or relatives	15	9	4.06*
Church or community activities	17	10	5.80*
Having children's friends in	14	8	3.95*
Hobbies or lessons for siblings	10	7	1.12
House they were living in	5	7	.34
Savings or insurance plans	13	11	.62

** Significant at the .01 level.

* Significant at the .05 level.

areas. Families in which C/F had been diagnosed for the shorter time of three years or less had given up (1) several activities away from home and (2) having the children's friends in more frequently than families in which C/F had been diagnosed for longer than three years. When changes in couple activities were analyzed by chi-square (Table 6), it was also found that parents of children diagnosed for the shorter time had significantly less time and energy for evenings out, but had made the least change in doing things with their other children. The greatest changes in most family and couple

TABLE 6

CHANGES COUPLE HAD MADE AS RELATED TO LENGTH OF TIME SINCE C/F WAS DIAGNOSED IN FAMILY

Activities Couple Had Given Up:	Number of Yes Answers		
	Diagnosed 3 yrs or Less (N = 21)	Diagnosed More Than 3 yrs (N = 16)	Chi-square
Evenings out as a couple	19	11	2.79†
Planning family activities	16	10	.82
Sexual relations of marriage	12	8	.19
Entertaining adults	15	11	.03
Doing things with siblings	8	11	3.42
Church, clubs, hobbies	18	11	1.54

†Significant at the .10 level.

activities were made or recognized in the earlier part of the illness. Families tended to give up activities outside the home; parents tended to devote more time to both the C/F child and well children within the home and less time to their own activities.

Communication of Mother with Other Family Members

Mother-Husband.-- The 41 mothers who had husbands present in the home indicated that they discussed most frequently the progress of the child's illness and how to meet the cost of the care (Table 7). They discussed the child's treatment, school and play activities, and family activities somewhat less often. They least often discussed having or not having another child; over half of the mothers said that they seldom or never talked about it.

TABLE 7

FREQUENCY OF COMMUNICATION OF MOTHERS WITH THEIR HUSBANDS[1]

Topics	Frequency Discussed		
	Seldom or Never	Occasionally	Often
Progress of child's illness	4	15	22
How to carry out treatment	10	13	18
How to meet cost of care	8	10	22
Having another child	22	8	11
Activities for C/F child	12	11	17
Future plans for child	10	14	17
Changes in family activities	14	13	14

[1] 41 mothers reporting.

Mother-C/F Child.-- In 27 families where a C/F child was five years old or older, the mothers most frequently talked about the daily treatment, how the child could help with it, and his daily activities (Table 8). The mothers tended not to talk about the illness or to help the child explain it to other children.

Mother-Siblings.-- Twenty-nine families had other well children who were five years old or older. Mothers discussed the treatment and care of the C/F child more frequently with other children in the family than limitations of activities due to C/F (Table 9).

TABLE 8

FREQUENCY OF COMMUNICATION OF MOTHERS WITH C/F CHILD[1]

Topic	Frequency Discussed		
	Seldom or Never	Occasionally	Often
What the illness is	11	12	4
Why treatment is needed	4	12	11
How to help with own care	7	5	15
Why activities are limited	9	8	10
What to tell other children	16	9	2

[1] 27 families with C/F child 5 years or older.

TABLE 9

FREQUENCY OF COMMUNICATION OF MOTHERS WITH WELL SIBLINGS[1]

Topic	Frequency Discussed		
	Seldom or Never	Occasionally	Often
Why C/F child needs treatment	7	11	11
Why C/F child cannot do some things	9	13	7
Why parents are not free sometimes	13	9	7
Why money may be limited	12	11	6
How to get along with C/F child	12	7	10

[1] 29 families with siblings 5 years or older.

Communication Related to Length of Diagnosis

When families in which C/F had been diagnosed for three years or less were compared by chi-square analysis with those in which it had been diagnosed longer, significantly more communication was noted in the first group, particularly between the mother and her husband. Table 10 shows that the difference in parental communication between the two groups was highly significant concerning treatment for the child and having or not having another child. There was also significantly more communication between parents in the group which had been diagnosed for a shorter time on most of the other topics.

TABLE 10

MOTHER-HUSBAND COMMUNICATION AS RELATED TO LENGTH OF TIME SINCE C/F WAS DIAGNOSED IN FAMILY

Topic	Number of Yes Answers		
	Diagnosed 3 yrs or Less (N = 21)	Diagnosed More Than 3 yrs (N = 20)	Chi-square
Progress of child's illness	21	16	4.65*
How to carry out treatment	20	11	8.99**
How to meet cost of care	20	13	5.96*
Having another child	15	4	10.90**
Activities for C/F child	14	14	.05
Future plans for child	18	13	2.38†
Changes in family activities	17	10	4.36*

** Significant at .01 level.

* Significant at .05 level.

† Significant at .10 level.

When the illness had been diagnosed for a shorter time, mothers also discussed with the siblings (1) why parents are not free and (2) how to get along with the C/F child significantly more often than other topics (Table 11). The only significant difference related to length of illness found in the communication of mothers with the C/F child concerned what to tell other children about the illness (Table 12).

Communication Related To C/F Child's Condition

The group of families was also divided according to the mother's definition of her C/F child's condition; good or poor. When tested by chi-square, significantly more frequent communication between parents was found on several topics when the child was considered in poorer health (Table 13); the difference in discussion of treatment was highly significant. Why parents are not free to do things was discussed significantly more often with the C/F child's siblings when the C/F child was described as being in poor health (Table 14). There were no significant differences between the two groups in communication of the mother with the C/F child (Table 15).

TABLE 11

MOTHER-SIBLING COMMUNICATION AS RELATED TO LENGTH OF TIME SINCE C/F WAS DIAGNOSED IN FAMILY

Topic	Number of Yes Answers		
	Diagnosed 3 yrs or Less (N = 12)	Diagnosed More Than 3 yrs (N = 16)	Chi-square
Why C/F child needs treatment	9	11	.13
Why C/F child cannot do some things	9	10	.49
Why parents are not free sometimes	9	5	5.25*
Why money may be limited	9	8	1.80
How to get along with C/F child	9	7	2.73†

* Significant at .01 level.

† Significant at .10 level.

TABLE 12

MOTHER-C/F CHILD COMMUNICATION AS RELATED TO LENGTH OF TIME SINCE C/F WAS DIAGNOSED IN FAMILY

Topic	Number of Yes Answers		
	Diagnosed 3 yrs or Less (N = 9)	Diagnosed More Than 3 yrs (N = 18)	Chi-square
What the illness is	5	10	.00
Why treatment is needed	9	14	2.35
How to help with own care	8	11	2.22
Why activities are limited	6	12	.00
What to tell other children	6	6	2.70†

† Significant at .10 level.

TABLE 13

MOTHER-HUSBAND COMMUNICATION AS RELATED TO C/F CHILD'S CONDITION

Topic	Number of Yes Answers		
	Good Condition N = 22	Poor Condition N = 19	Chi-square
Progress of child's illness	20	17	.02
How to carry out treatment	13	18	7.03**
How to meet cost of care	15	18	4.58*
Having another child	8	12	2.93†
Activities for C/F child	15	14	.15
Future plans for child	16	15	.21
Changes in family activities	13	15	1.86

** Significant at .01 level.

* Significant at .05 level.

† Significant at .10 level.

TABLE 14

MOTHER-SIBLING COMMUNICATION AS RELATED TO C/F CHILD'S CONDITION

Topic	Number of Yes Answers		
	Good Condition (N = 16)	Poor Condition (N = 12)	Chi-square
Why C/F child needs treatment	11	10	.78
Why C/F child cannot do some things	9	10	2.31
Why parents are not free sometimes	6	9	3.88*
Why money may be limited	8	8	.78
How to get along with C/F child	10	7	.05

* Significant at .05 level.

TABLE 15

MOTHER-C/F CHILD COMMUNICATION AS RELATED TO C/F CHILD'S CONDITION

Topic	Number of Yes Answers		
	Good Condition (N = 12)	Poor Condition (N = 15)	Chi-square
What the illness is	7	8	.07
Why treatment is needed	10	13	.06
How to help with own care	9	10	.22
Why activities are limited	7	12	1.50
What to tell other children	6	5	.77

Stresses of Parents

When asked what stresses the couple had experienced during their child's illness, fear and worry concerning the child's life and health were mentioned by 27 mothers, financial worries were indicated by 16, fatigue related to the routine of care was listed by nine, and concern for the effect of the illness on family life was mentioned by eight.

Sources of Help Used By Families

When asked to identify the greatest sources of help for herself and her family in meeting problems connected with her child's illness, thirty-one mothers listed a doctor, hospital, or clinic, nineteen stated their faith, God, or church, seven mentioned family and relatives, seven listed friends, and five specifically mentioned other C/F parents. Financial help was listed by seven mothers.

Characteristics of Interview Respondents

Fifteen of the 42 mothers who responded to the questionnaire were interviewed. There were only slight differences between the group of families who were interviewed and the entire questionnaire group. The mean age of the 16 C/F children in the 15 families was 8.4 years as compared to 6.87 years in the entire group of families who responded to the questionnaire. The mean length of time C/F had been diagnosed in the family was 6.1 years in the interview group and 5.3 years in the questionnaire group. In eight of the fifteen families, a C/F child had been hospitalized during 1964, and the mean cost of medicine and equipment was $837 ($964 in questionnaire families). The mean ages of the parents and the mean length of marriage were similar in the two groups. The interviewed families ranged in size from one to six children; the mean was 2.73 children. Two families had incomes under $5,000; twelve from $5,000 to $10,000; and one family, over $10,000.

Interview Responses

Ways Families Met Treatment Needs of C/F Child

Of the fifteen mothers interviewed, 14 stated that they were giving their C/F child medication, nine were using a mist-tent or humidifier at night, and five were giving inhalation treatments. The mothers found it difficult to estimate their time required for this treatment; estimates varied from none to three hours per day. When asked if they had been able to buy the prescribed medicine and equipment, 14 stated that they were meeting drug bills. One family could not afford the medicine so a neighbor had purchased it for awhile; the child was not receiving medication at the time of the interview. Two mothers said that their child needed a new mist-tent which they could not afford, and two other mothers said that their husbands had made a mist-tent because they could not afford to buy one (Approximate cost, $350).

Changes in Family Life Due to Child's Illness

Effect on Time and Finances.-- Eleven mothers expressed the need to be at home in order to watch the C/F child. The most frequent changes in daily routine were getting up earlier in order to do treatment before school, and being free to take the child to the doctor or to care for the child when ill. Two mothers of school-age children had started working full-time in order to help with expenses. One mother of an 18-month-old child worked part-time evenings when her husband could be home in order to be out of the home for a while each day. The other 12 mothers stated that they probably would not have been employed anyway. All of the mothers said that their husbands had not changed their daily routines on account of the C/F child's care; however, two husbands had taken extra work in order to increase the family income. Thirteen mothers said that the family had cut down on other expenses in order to meet the C/F child's needs; one family had sold a boat and given up week-ends on the river, one had sold a piano, another had put off dental work for the other children. Three families were repaying loans for medical expenses at the time of the interviews.

Effect on Family Size.-- When asked whether the C/F diagnosis had affected their plans for the size of the family, eight mothers said that it had, three mothers said that it had not and four mothers said that they would not have had another child anyway. One of the mothers who said that C/F had not changed their plans explained that the C/F child was adopted.

Effect on Siblings.-- Three of the families had no well siblings, nine mothers could not identify any effects of C/F on the other children, and three mentioned that the other children felt upset, irritated, or sympathetic.

Effect on C/F Child.-- When asked how the C/F child felt about the illness, seven mothers said that the child accepted the treatment as part of the daily routine, four said that the child resented the time necessary or being different from other children, two stated that the child was too young to know, and two mothers said that they had not discussed the illness with the child.

Effect on Husband-Wife Relationship.-- In all of the families interviewed, the marriage relationship seemed to be stable. The mothers said that the child's illness had united rather than separated the couple. However, some strains were present. One mother said that her husband did not believe that the child had C/F, and therefore they were no longer treating the child for it. In another family the mother said that her husband left all decisions about their son's care to her, and she worried about doing the right thing. One wife was concerned because her husband had given up his hobbies and activities away from home.

Sources of Help Used by Families

The only sources of advice or help on treatment and care or planning time for the treatment and care were the doctor and hospital personnel. One family had consulted a budget planning service in order to get a loan. Six of the mothers had talked with their minister about the C/F child's illness and three had talked with school personnel. One mother reported that a school guidance counselor had referred her 17-year-old son to the Vocational Rehabilitation office for help in planning college work.

Future Plans and Expectations

When asked whether they expected their child's treatment to be easier or harder to manage in the future, five said that they thought it would be easier, six thought it would be harder, and three said that they did not know as it would depend on the child's condition. The mothers who thought it would be easier thought that the child could help more as he became older. The mothers who thought it would be harder thought that the child's condition would be worse or that the child would resist treatment more as he became older.

There was more uncertainty about the future in regard to finances. Seven mothers said that they did not know whether the cost would be easier or harder to manage; the expense would depend on the child's condition. Three thought it would be easier and three thought it would become more difficult. Two did not consider expenses a problem; one family received medical care through the Air Force and one family had an income over $10,000 per year.

When asked whether they would use a family counseling service if it were available, seven mothers said they would, six said that they did not need it now, and two said that they would hesitate to talk with someone outside the family.

When asked whether counseling in regard to treatment, finances, or the worry after illness would be most useful to them, seven mothers said worry, and six said finances. None of the mothers thought the home treatment was the major problem. These mothers said that they most needed help when C/F was first diagnosed or when the child was hospitalized.

CHAPTER IV

DISCUSSION AND SUMMARY OF DATA

The C/F Children

The C/F children in this study varied in their state of health as described by Landauer (1963). Three-fourths of the mothers described the child's condition as good or nearly normal; one-fourth as fair, poor, or severe. Most of the school-age children were in school; only two mothers stated that their five-year-olds were not well enough to start school. Most school-age children were in grades appropriate for their ages; one twelve-year-old was attending special education classes. During the interviews, several mothers mentioned that their children were absent occasionally, but were able to keep up with their work. One mother stated: "Our daughter (age 11) leads a normal life; goes to Scouts, swimming, roller skating, and plays football with neighbor children"; another mother described her 13-year-old son as coughing constantly, nervous, and with more clubbing of the fingers. As a group, most of the C/F children were leading fairly normal lives, but were ill more frequently than normal children as evidenced by the fact that over half of them were hospitalized at some time during the previous year.

Treatment

The treatment regimen which the mothers said they were following at home varied with the child's condition. Most of the children were receiving medication with meals; over half were sleeping in some kind of a mist-tent and were receiving inhalation treatments. No attempt was made on the questionnaire to determine any difference between what had been prescribed for a child and the treatment which was being carried out. During the interviews, mothers were again asked to describe the child's daily treatment, and also to estimate the time spent. Most of the 15 mothers interviewed seemed to be well-informed about their child's condition and treatment, and to be conscientious about the daily routine of treatment; however, three mothers indicated that they were not carrying out daily treatment on a regular basis. Two of these mothers had new babies, and the third mother had been in ill health herself.

The relationship between the child's condition and treatment was shown by the chi-square analysis of the difference in communication between families where the C/F child was described as being in poor condition and families where the child was in good condition. When the C/F child was defined as being in poorer condition there was significantly greater communication between parents about treatment and between the mother and the C/F child's siblings about why parents were not free. Mothers were asked, during the interviews, whether they expected their child's treatment to be easier or harder to manage in the future. Their answers indicated their expectations of the child's condition in the future, which showed that they related treatment to the child's condition. The kind and amount of treatment needed by the child and therefore the time required depended on his condition.

Ways Families Met Treatment Needs of C/F Child

Treatment was carried out by the mothers, but over two-thirds of the husbands helped occasionally or often. Since all of the husbands were employed and only nine of the 42 mothers worked full-time outside the home, the husband's help represented part of their limited time at home. Grandparents helped occasionally or often in 11 families; however, the C/F child's brothers and sisters rarely helped. The parents were taking the major responsibility for daily care of the child by providing the time and energy required for treatment.

Questionnaire responses showed that parents had less time and energy for most of the activities which were listed. Mothers who were interviewed did not feel that the time and energy required by the treatment was a major problem; however, they felt that it was necessary to be at home or available when needed. The uncertainty of the C/F child's condition from day-to-day, as represented by the frequent hospitalization, may account for the mother's need to be at home more than the time actually required for treatment. One mother said that she felt better taking care of her son herself; another said that no one else would know what to watch for as well as she did.

The cost of medicine and equipment for home treatment (mean, $964.85) was similar to estimates by Anderson (1960) and the National Cystic Fibrosis Research Foundation (1963). The cost was being paid by the families. At the time of the study, neither Kansas or Missouri statutes included C/F in their Crippled Children's benefits. Some families were purchasing drugs at reduced cost through an arrangement of the clinic with a cooperating drug store in Kansas City. The 20 families who were attending the C/F clinic were paying only $3.00 per visit for physician's services and laboratory tests. Without these helps, the costs to families would have been greater.

Thirty-two of the 42 families had a yearly income between $5,000 and $10,000. Questionnaire responses showed that families most frequently gave up vacations or trips and savings, and that 12 of the 42 families had given up the house they were living in; there was no relationship between these and the length of the illness. Cost of treatment was one of the topics discussed most frequently by all parents. The cost was discussed significantly more frequently by parents when the illness had been diagnosed for a shorter time and when the child was in poorer condition. (The cost is likely to be greater at these times; the purchase of equipment is an initial expense, and the child in poorer condition requires more medication.) Financial worries were indicated by over one-third of the questionnaire respondents.

Interview responses indicated that families were meeting the expenses of their child's medication; however, two mothers said that the child needed equipment which they had been unable to purchase. Two fathers and three mothers had taken additional work in order to increase the family income. All of the mothers interviewed said that they had cut down on other expenses and were concerned about their family finances; three of the families had found it necessary to borrow money for hospitalization expenses.

Turk (1964) found that the 25 families in her study were not financially deprived; they had not had to give up such things as eating out or babysitters, and had not changed their standards of housing. The families in the present study, as a group, were meeting the expenses of the child's illness; however, they were doing so by changing their standard of living and sacrificing their savings.

Changes in Families Due to C/F

Family Size

The mean ages of the parents and the mean length of marriage show that as a group, these families were within the child-bearing stage. It is the practice (Schwachman, 1957) for physicians to inform parents of the genetic potential of the disease as soon as it is definitely diagnosed in a child. Five of the 42 families in this study had two C/F children and one family had three. Four families had previously lost a C/F child. Eight families had a C/F child or children only. Twenty-one of the families had a child or children younger than a C/F child. By comparing the time of first diagnosis with the ages of the children, it was determined that 14 of the 42 families had one or more children at least a year after C/F was first diagnosed in the family.

Turk (1964) found that parents were significantly deprived of sexual relationships. Of 38 mothers who responded to a similar questionnaire item in the present study, five stated that they had less time and energy for sexual relations and 14 stated that they sometimes had less time and energy; however, it was the area of least change in the activities listed. There was no significant difference in sexual relations related to length of C/F diagnosis. The question of having or not having another child was discussed seldom or never by 22 of 41 mothers. However, when analyzed by chi-square, there was a highly significant difference in the frequency of discussion related to length of illness, with parents discussing the question more when the illness had been diagnosed for a shorter time. There was also a difference in communication between the mother and her husband about having another child related to the C/F child's condition, with significantly more discussion between parents when the child was in poorer condition.

Burgess (1953) described communication as the mechanism through which family members modify each other's behavior; Hill (1949) stated that a period of crisis and change is followed by a level of adjustment, once new patterns are found. Turk (1964) found that a significant area of breakdown in communication between parents was in regard to having another child. The further analysis of the present study on this question indicated that parents did discuss having or not having another child in families where C/F had been diagnosed for a shorter time and the C/F child was in poorer condition. Possibly families in which the child was in better condition or C/F had been diagnosed for a longer time communicated less frequently because a change in behavior was not perceived as necessary or because an adjustment had already been made.

During the interviews, mothers were asked whether the C/F diagnosis had influenced the size of their families. Eight of the 15 mothers said that it had, and four said that they would not have had more children anyway.

The incidence of multiple C/F children in families in this study is further evidence that parents need to be aware of the hereditary aspect of the disease. Responses indicated that parents discussed having or not having another child, that sexual relations were somewhat reduced, and that some parents had limited the size of their families as a result of the C/F diagnosis; however, family composition indicated that one-third of the parents had another child after the C/F diagnosis.

Social Activities

Turk (1964) found that parents felt deprived of the usual interpersonal relationships with friends and were unable to follow through on family activities. Questionnaire responses in the present study indicated that family members had fewer contacts with persons outside the home due to the C/F child's illness. Over half of the families had given up visits to friends and relatives, church and community activities, and having the children's friends in at least some of the time. There was a significant difference in all three of these areas related to length of illness, with more changes in the families in which the illness had been diagnosed for the shorter time.

Over half of the parents had less time or energy for planning family activities, entertaining adults, and church, clubs, or hobbies. Although half of the parents had less time or energy for doing things with siblings; there was significantly less change in families in which C/F had been diagnosed a shorter time which indicated that parents gave up their own activities rather than limit their time with other children in the family. Contacts with persons outside the home were also noted in the question concerning whom the mother discussed the child's illness with; 29 of 41 mothers discussed the illness with friends and neighbors, and 18 had discussed it with a clergyman.

Zimmerman (1960), in his study of successful families, found that most good families had five close-friend units which were located near-by and which were long-lasting friendships. The family friends provided children with models who had values similar to those of their parents. No attempt was made to evaluate the success of families in the present study; however, the tendency to withdraw from groups in the community and the limitation of contacts with persons outside the home over a long period of time could adversely affect family friendships.

The questionnaire items concerning communication between family members showed that parents discussed the C/F child's illness and the cost of care more frequently than changes in family activities. Fourteen of the 41 mothers seldom or never discussed changes in family activities with their husbands. Treatment was also discussed more frequently than changes or limitations in activities both with the C/F child and other children in the family. When the illness had been diagnosed for a shorter time there was significantly more communication between the mother and her husband concerning changes in family activities. Mothers discussed why parents were not free significantly more frequently with other children in the family both when illness had been diagnosed for a shorter time and when the C/F child was in poorer condition. The frequency of communication on these topics showed a tendency for the mother to focus on the ill child's needs and to adapt other activities accordingly without discussing changes with other family members.

The 15 mothers who were interviewed noted few effects of the illness on other children in the family. One mother talked about her C/F child for over an hour without mentioning that she also had a 16-year-old son, until asked about him.

When asked, on the questionnaire, what stresses the couple had experienced during their child's illness, fear and worry concerning the child's life and health were mentioned by 27 mothers, and concern for the effect of the illness on family life by eight. Seven of the 15 mothers interviewed said that worry for the child had been the major problem of the illness. Four of the fifteen mothers were devoting considerable time to work with other C/F parents in foundation chapter activities. Concern for the ill child, as well as limitations of time and money, tended to influence the mothers decision-making process in regard to planning family activities. One mother stated:

> Our family life is centered around our child. If he is sick and cannot go out, we arrange our time so one of us is home at all times. If my husband and I happen to go out for dinner, we see that he has had all his medicines and is put to bed properly before we ever leave the house. Our girls understand the condition of their brother and are very sweet about it all. It is hard on them at times, but we try to do all we can for them.

The uncertainty of the C/F child's condition also limited the mothers' freedom to plan activities ahead of time. A mother who said that she lived "day-to-day and week-to-week" expressed the attitude of many of the mothers who were interviewed.

Sources of Help Used by Families

Thirty-one of 42 mothers listed medical personnel as the greatest source of help on problems connected with their child's illness. The mothers who were interviewed seemed well-informed about their child's condition and treatment. None of the interview respondents thought that additional help with treatment was a major problem, so evidently believed that they were receiving adequate instruction. One mother wrote that her greatest source of help was the C/F clinic in Kansas City; "we know it's there, that someone cares, and that we're doing all we can for our daughter."

Very little help from community or paid nurses with the child's actual care at home was received by families.

Despite evidence of financial stress, only one of the 15 families who were interviewed had sought or received help with financial planning; six thought counseling help was most needed in this area.

Mothers talked with some persons who could provide emotional support; their husbands, parents and relatives, and friends and neighbors. However, one mother said that talking to friends, relatives, and clergyman was of no real help; "all they can offer is sympathy, but no real understanding." Several mothers expressed appreciation for contacts with other C/F families, and one mother, who wrote a long letter in addition to the questionnaire, stated: "it's nice to talk about your child to someone who understands."

Many mothers gained support through their religious beliefs; one said that her faith "that God would not ask more of her than she was capable of meeting with His help" was her greatest source of help. Others appreciated the fact that their child "could have been born with something worse," or expressed hope that the child would continue to improve and be able to lead a normal life.

The acceptance of responsibility by mothers, their hopefulness, and their willingness to sacrifice for their children's well-being which was shown during the interviews was evidence that they had drawn strength from inner resources with which to meet the crisis of the illness.

Contacts with professional persons in the community who might have been of help were very infrequent. Perhaps the limited contacts of parents outside the home was a contributing factor. Frank (1956) stated that "there is starvation in the midst of plenty" when families cannot establish a reciprocal relationship with the community they live in; that the inability to relate themselves to others prevents families from drawing strength from without.

When asked whether they would use a family counseling service if it were available, about half of the mothers who were interviewed said that they would. A few mothers expressed some hesitancy about discussing family matters with outsiders; however, they were extremely cooperative about responding to the questionnaire and interview.

CHAPTER V

CONCLUSIONS

1. Most of the families in this study were adequately meeting the C/F child's treatment needs at home; most of the C/F children were able to attend school and to lead fairly normal, active lives.

2. The amount of time and money required for treatment at home was determined by the severity of the C/F child's condition. Family adjustment, as indicated by frequency of communication, was significantly related to the child's condition.

3. Treatment was carried out by both parents; grandparents also helped, but help was seldom obtained outside the family.

4. The uncertainty of the C/F child's health and the need to be available determined the mother's routine more than the actual time spent on treatment. Mothers thought they had sufficient medical instruction to carry out the treatment.

6. Families showed evidence of financial stress although they were presently meeting the costs of medicine and equipment for home treatment. The yearly cost, the lack of savings, and the range of ages of the C/F children in the study indicated that families may find economic stability difficult to maintain over a long period of time.

6. Parents were aware of and concerned about the hereditary aspect of C/F, but showed evidence of difficulty in readjusting future plans for a family.

7. The contacts of all family members with persons outside the home were reduced because of the illness. Significantly greater changes in activities were made in families in which C/F had been diagnosed for a shorter time. The limitation of activities was caused partly by limited time and money; however, it was also caused by a focusing of attention and concern on the ill child with consequent inattention to the needs of other family members. The mean family size was 3.0 children; there were also normal children to consider.

8. Communication between the mother and other family members concerning many aspects of the illness was limited. The ability of all family members, both individually and as a group, to adjust to the changed conditions of the illness depends on their ability to exchange ideas, attitudes and values.

9. Most professional help used by families of the C/F children was of a medical nature; families were not receiving professional help with family adjustments.

As a result of the findings of this study, it was concluded that families of C/F children needed and would benefit from family counseling in adjusting to the stresses of the illness on family life.

CHAPTER VI

IMPLICATIONS FOR COUNSELING

1. The focus of counseling should be on enabling the C/F child and the other family members to live together at home. Families need help to recognize and plan to meet the needs of all family members over a long period of time.

2. Family counseling available through a medical facility would be most accessible and readily available to C/F families; i.e. the C/F Clinic in Kansas City.

3. Counseling available early in diagnosis when greatest changes and adjustments are being made would be most helpful to families in reorienting family goals and values.

4. Counseling should be concerned both with the unique aspects of the disease and with family life. Help with problems of integrating treatment into family routines, planning for long-range family financial security, and birth-control should be available.

5. Counseling should help parents communicate with each other, with their children, members of the extended family, friends, and community persons and agencies concerning the illness and treatment needs. Improved treatment and reduction in mortality encourage sharing a more positive attitude toward C/F.

6. The parents of C/F children are normal people who are concerned about taking good care of their children. Counselors should be persons

who can help parents clarify their feelings and plan appropriately for themselves and other children in the family as well as for the C/F child. Home economics training in family relationships and in meeting family needs through the management of time, money, and energy would be valuable, as would training in counseling. Counselors would need to be familiar with the unique aspects of C/F and the treatment, but would not need extensive medical knowledge which could be provided by the physician.

APPENDIX

TABLE 16

AGE DISTRIBUTION OF C/F CHILDREN

Years of Age	Number of Children	Years of Age	Number of Children
1 or less	3	10	3
2	6	11	0
3	4	12	3
4	5	13	1
5	6	14	1
6	4	15	3
7	3	16	0
8	2	17	2
9	3		

TABLE 17

LENGTH OF TIME SINCE C/F WAS FIRST DIAGNOSED IN FAMILY

Years	Number of Families	Years	Number of Families
1 or less	9	9	3
2	6	10	2
3	6	11	2
4	3	12	1
5	3	13	2
6	1	14	1
7	1	15	0
8	1	16	1

KANSAS STATE UNIVERSITY

Manhattan, Kansas 66504

Department of Family and Child Development
Justin Hall

March 4, 1965

The Family and Child Development Department at Kansas State University and the Kansas City chapter of the Cystic Fibrosis Foundation are cooperating on a study of the effects of cystic fibrosis on family life.

We know that the illness of one person puts many stresses on other members of the family. With cystic fibrosis, the amount of care carried out at home may make normal family life difficult. With a better understanding of the kinds of problems which can arise, plans can be made for counseling services which will be most helpful to families.

Your experiences as the mother of a C/F child can be very useful in indicating how other parents can best be helped. Will you take part in the study by completing the enclosed questionnaire and returning it to us? The questionnaires are identified only by number; you may be assured that the names of cooperating families will not be used in the report of the study.

Your help with this study will be greatly appreciated. Please do return the questionnaire at your earliest convenience.

Sincerely yours,

(Mrs.) Gretchen Bonnewell

1. How long ago was C/F first diagnosed in your family? ________________

2. Your children are:

boy or girl	age	grade in school	does child have C/F

3. Would you describe your C/F child's (or children's) physical condition now as <u>nearly normal</u>, <u>good</u>, <u>fair</u>, <u>poor</u>, <u>or</u> <u>severe</u>?

child (age)	condition now	How long has child been under treatment for C/F?	How has condition changed since treatment began?

4. Is your husband present in the home? _______

5. How long have you and your husband been married? _______yrs.

6. What are your ages? Yours ______ Your husband's ______

7. Describe your husband's occupation.

8. What is your occupation, if employed?

9. Is the total yearly income of your family under $5,000______, $5,000 to $10,000 ______, or $10,000 or over ______?

10. About what did the <u>medicine</u> and <u>equipment</u> needed for taking care of your C/F child (or children) cost your family in 1964? $____________

    (please do not include hospital expenses covered by insurance, or services provided at the clinic.)

11. Was your C/F child hospitalized at any time last year? ________

12. Do your parents or your husband's parents live within five miles _____, within 100 miles _____, or further away _____?

Please check each phrase in the space which describes your family best. If a question does not apply to your family, draw a line through it.

1. How often is help with the daily treatment or care of your C/F child given by:

	Seldom or Never	Occasion-ally	Often
(a) your husband?			
(b) one of the child's brothers or sisters?			
(c) a grandparent or other relative?			
(d) a neighbor or friend?			
(e) a volunteer or community nurse?			
(f) a paid helper or nurse?			
(g) other?			

2. How often do you discuss your child's illness with:

	Seldom or Never	Occasion-ally	Often
(a) your husband?			
(b) your parents and relatives?			
(c) your husband's parents and relatives?			
(d) friends, neighbors?			
(e) your child's teacher?			
(f) your clergyman?			
(g) public health or visiting nurse?			
(h) a counselor?			

3. How often do you and your C/F child talk about:

	Seldom or Never	Occasion-ally	Often
(a) what the illness is?			
(b) why daily treatment is needed?			
(c) How to help with his own care?			
(d) why some activities are limited?			
(e) what to tell other children about the illness?			

4. Since your child has been under treatment for cystic fibrosis, has it been necessary for your family to give up:

	Yes	Sometimes	No
(a) baby-sitters?			
(b) eating out?			
(c) vacations or trips?			
(d) visits to friends or relatives?			
(e) church or community activities?			
(f) having the children's friends in?			
(g) hobbies or lessons for other children?			
(h) the house you were living in?			
(i) savings or insurance plans?			
(j) other?			

5. How often do you talk with other children in your family about:

	Seldom or Never	Occasion-ally	Often
(a) why the C/F child needs daily treatment?			
(b) why the C/F child cannot do some things?			
(c) why parents are not free to do some things?			
(d) why money may be limited?			
(e) how to get along with the C/F child?			

6. When you and your husband talk together about your sick child, how often do you talk about:

	Seldom or Never	Occasion-ally	Often
(a) progress of the child's illness?			
(b) how to carry out treatment instructions?			
(c) how to meet the cost of medical care?			
(d) having or not having another child?			
(e) school and play activities for the child?			
(f) future plans for the child?			
(g) changes in family activities due to illness of the child?			

7. Since your child has been sick, have you and your husband found that you have <u>less</u> time and/or energy for:

	Yes	Sometimes	No
(a) evenings out as a couple?			
(b) planning family activities?			
(c) sexual relations of marriage?			
(d) entertaining adult friends or relatives?			
(e) doing things with other children in the family?			
(f) church, clubs, hobbies?			
(g) other?			

Please answer briefly in your own words.

1. What routine things need to be done in a typical day for the treatment and care of your C/F child?

2. What stresses have you and your husband, as parents, experienced during the course of your child's illness?

3. If you had a free day in which to do anything you pleased, what would you do?

4. What have been the greatest sources of help for you and your family in meeting problems connected with your child's illness?

INTERVIEW SCHEDULE

I. There is a great deal of difference in the treatment each C/F child receives.

1. What needs to be done each day for your child now?

2. About how much time does this take each day?

3. What changes have you made in your own routine in order to have time?

4. Has the care affected your working or not working outside the home?

5. How has your husband changed his routine?

6. Who has given your family advice or help on planning time for treatment or learning to give treatments?

7. Do you think that it will get easier or harder to take time for this care as the child gets older? Why?

II. The cost of medicine, equipment, and hospitalization has been fairly high, and as yet, C/F is not under Crippled Children's Acts in Kansas and Missouri.

1. Have you been able to buy the things that the doctor recommended for your child?

2. What changes has your family made in order to be able to afford these things?

3. Have you consulted anyone about your family budget? Who?

4. As you look ahead, do you think it will get easier or harder for your family to manage these expenses?

III. C/F was probably unexpected for your family. You have needed to make some adjustments.

1. Has C/F affected your plans for the size of your family?

2. How do you think it has affected your other children?

3. How does your C/F child feel about the illness?

4. Has this illness made you and your husband feel closer, or have the problems connected with it seemed more to cause disagreements?

5. If it were available, would you make use of a family counseling service?

6. Do you think (in your case), counselors would need to be able to help families with (1) managing time for treatment, (2) planning finances, and/or (3) helping adults and children with worries and feelings about the illness?

7. Has there been any particular time when you've been most worried, or when you've most needed help?

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EFFECTS OF CYSTIC FIBROSIS ON FAMILIES

by

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B. S., Iowa State University, 1951

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MASTER OF SCIENCE

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The diagnosis and treatment of cystic fibrosis of the pancreas (C/F), a generalized, hereditary disorder of children, have greatly improved in the last ten years. As a result, the number of children with C/F is increasing, and more families are assuming responsibility for the long-term treatment and care needed by children. Little research has been done on the effect of the care of a C/F child upon the family unit, or on the community services which would halp families adjust to the crisis of a C/F child.

The C/F clinic in Kansas City, established by the local chapter of the National Cystic Fibrosis Research Foundation, planned to add family counseling to the medical services already provided for C/F families. The purpose of this study was to determine family counseling needs by (1) investigating ways that families of C/F children had adapted to the home treatment needs of the ill child, (2) identifying the sources of stress and its effects on family life, and (3) determining the sources of help used by families.

Questionnaires were sent to 23 mothers of clinic patients and 92 members of the Kansas City chapter of the National Cystic Fibrosis Research Foundation in an effort to locate as many families with C/F children as possible in Kansas and Missouri. The 42 questionnaires used in the study represented families with one or more C/F children living at home in February-March, 1965. Twenty of the families were using clinic facilities, and 22 families were using private medical services. The questionnaire was used to collect factual information about each family and how it was meeting the needs of a C/F child. It consisted of a face sheet, seven multiple-choice questions, and four free-response questions which were adapted from a questionnaire developed by Turk (1964). Fifteen of the 42 mothers were interviewed to gather data on their attitudes and plans for the future.

The 49 C/F children in the 42 families ranged in age from under one year to 17 years, with the mean age 6.87 years. The length of time since C/F had first been diagnosed in the family ranged from less than one year to 16 years; it had been diagnosed for three years or less in half of the families. Twenty-two mothers described their C/F child's condition as good or nearly normal; nineteen as fair, poor, or severe. Questionnaire responses were analyzed by chi-square in relation to length of diagnosis and in relation to the child's condition.

As a result of the findings of the study, it was concluded that families needed and would benefit from family counseling. While most families in the study were adequately meeting the C/F child's treatment needs at home, there was evidence of financial stress, concern of parents for the hereditary aspect of C/F, inadequate communication between family members, and a reduction of contacts of all family members with persons outside the home. Adjustments, as indicated by changes in family activities and frequency of communication, were significantly greater in families in which C/F had been diagnosed for a shorter time and in which the C/F child was considered in poorer condition. Families tended to focus on the immediate needs of the ill child rather than on the needs of all family members when making changes. Most professional help used by families was of a medical nature; families were not receiving professional help with family adjustments.

It was recommended that persons who would be most effective as family counselors would have a strong family life background and training in counseling. They would need to be able to help parents reorient family values and goals; to integrate treatment for the C/F child into family life through the management of time, money and energy; and to help family members increase their ability to communicate with each other.