Families of Adolescents with Cystic Fibrosis: Coping Behaviors Utilized in Managing the Stressors of Adolescence and Illness

by

Anne Camille Patton

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Abstract

Adolescents with cystic fibrosis and their families are in a vulnerable position because of the compounded stressors of adolescent development and management of a debilitating, fatal illness (Korsch, 1973; Patterson & McCubbin, 1983). The purpose of this exploratory study was to examine the coping behaviors utilized by adolescents and their families in response to identified stressors.

A convenience sample of 19 families (21 adolescents, 19 female parents, and 8 male parents) who received care from a large university regional center for cystic fibrosis participated. Three categories of perceived stressors were noted by these subjects. The adolescents identified day to day stressors in areas related to adolescent development, education, and management of the illness in their responses to the A-COPE instrument and interview questionnaire. The parents identified day to day stressors in areas related to spousal involvement, education of their adolescent(s), and management of the illness in their responses to the CICI:PQ instrument and the interview questionnaire.

Coping behaviors found helpful by adolescents for

managing their illness were low level activities, emotional connections, and self-reliance and positive appraisal. Professional support was rated as least helpful. Parent subjects reported the coping behaviors of praying, talking, crying, and busying self with other things as helpful for managing their adolescent's illness. Although the female parents utilized the behaviors, asking for help and yelling or slamming doors, more frequently than the male parent, there was total agreement reported by parents for making their adolescent comfortable or happy.

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CHAPTER ONE

PROBLEM DESCRIPTION

As the life expectancy of those with cystic fibrosis increases, an ever larger number reach adolescence. For these individuals, the unique stressors imposed by cystic fibrosis compounds the tumult experienced in adolescence. For their parents, the stressors of cystic fibrosis are added to those normally experienced by families with adolescents. Such stressor events cause a major reorganization of roles and tasks, and resulting in stress in family members. Stressors in this study are described as events that cause stress in family members and that are related to normal development and to the day to day care of the disease process.

Cystic fibrosis is a genetically transmitted disease of unknown biochemical etiology which primarily affects pulmonary, pancreatic, gastrointestinal, and sinus function. These organs suffer loss of viable tissue and death usually results from complications such as infection, obstruction, and malabsorption that occur from thick secretion accumulation (Blessing-Moore, 1979).

In the 1950s the average life span for a child with cystic fibrosis was 8 years. Recent medical advancements have increased this span so that now 80% of individuals with the disease can live to 20 years or more

(Blessing-Moore, 1979).

Day-to-day management of the illness is usually done by parents in the home. Treatment routinely includes an intensive regime of chest physiotherapy, often 2 or 3 times a day; nutritional supplementation; and medications. Frequently hospitalizations and physicians visits are still necessary to prevent the complications of thick secretion accumulation.

The adolescent with cystic fibrosis must cope with the limitations imposed by the disease itself as well as master the stressors of adolescence. Studies indicate that adolescents with cystic fibrosis have more difficulty than adolescents in accomplishing the developmental tasks of adolescence and in preparing for adulthood (Boyle, di Sant'Agnese, Sack, Millican, & Kulczycki, 1976; Landon, Rosenfeld, Northcraft, & Lewiston, 1980; Leichtman & Friedman, 1975; Lewiston, 1980; Pinkerton, 1969; Rosenlund & Lustig, 1973; Wolfish & McLean, 1974).

In addition, there is stress to family members. Cystic fibrosis can threaten the stability of the family. The stressors imposed by cystic fibrosis involving management of daily treatment regime, financial constraints, and limitations of leisure and personal time, can diminish the ability of the family to satisfy the physical and psychological needs of all its members (Denning, Gluckson, & Mohr, 1976; Lawson, 1977; McCollum &

Gibson, 1970; Tropauer, Franz, & Dilgard, 1970). Often the health of the ill member is compromised when the perception of family structure and function is threatened.

In conceptualizing coping behaviors in adolescents and families dealing with cystic fibrosis and normal developmental processes, it is necessary to look at the adolescent's and the family's ability for coping with change and the school and health system as sources of support. Coping is thus defined as an active transition between individuals with themselves and/or their environment in daily life events in order to alter a situation appraised as harmful or threatening (Lazarus, 1981).

Psychological research examines characteristics of cognitive appraisal in coping with the realities of the current situation (Lazarus, 1966); autonomy involving development and maintenance of interpersonal relationships (White, 1974; Murphy, 1963) and emotional organization including development of self confidence and self esteem in managing tension and stress (Lazarus, 1981). These three psychological characteristics are strongly related to social support theory in regard to obtaining adequate information and maintaining autonomy and self esteem. Social support is described as information which provides comfort, strength, or help to an individual to the family unit.

A review of the literature that examines the importance of such treatment is demonstrated by correlations

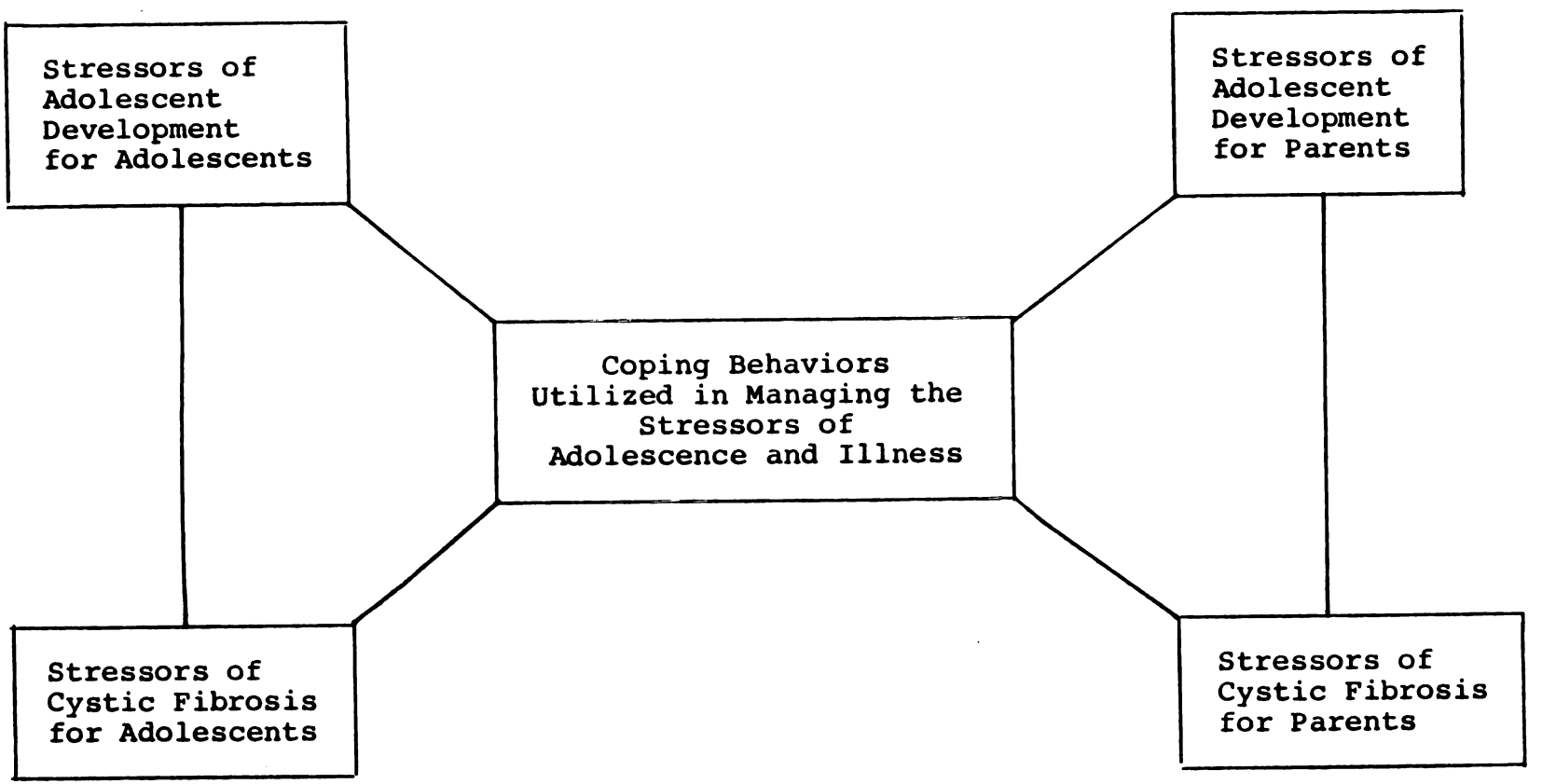
which show improved physiological and psychological well-being in individuals who, together with their families, consistently adhere to the treatment regime by utilizing helpful coping patterns (McCubbin, Patterson, & Wilson, 1979). Thus if helpful coping behaviors are not implemented the likelihood of family discord and poor management of the illness can increase if the members routinely utilize maladaptive behaviors such as depression, anxiety, and non-compliance in adapting to the stressors imposed by cystic fibrosis (Denning et al., 1976; McCubbin, Patterson, & Wilson, 1979; Mattsson, 1972; Steinhauer, Muskin, & Rae-Grant, 1974; Tropauer et al., 1970). However, the literature suggests that information on adolescents and family coping behaviors utilized in managing problems of chronic illness and in dealing with difficult life situations and normal adolescent development has not been addressed (McCubbin, Patterson, Cauble, Larsen, Comeau, & Skinner, 1981).

Problem Statement

Adolescents with cystic fibrosis and their families are in a vulnerable position because of the continuous daily stressors imposed by the illness. If they use coping behaviors that are helpful in dealing with identified stressors, they are better able to master their developmental tasks and achieve higher levels of physiological and psychological well-being (Figure 1). The purpose of this

Figure 1

Overview of Theoretical Formulation



study, then, is to examine the coping behaviors utilized by adolescents and their families in response to identified stressors. Specifically, the following questions are investigated:

1) What stressors do adolescents with cystic fibrosis identify?
2) What stressors do parent(s) of adolescents with cystic fibrosis identify?
3) What coping behaviors do adolescents with cystic fibrosis and their parent(s) use for management of the illness?

Assumptions

Adolescence in Western culture is a stressful period affecting not only adolescents but their family as well (Daniel, 1977; McCubbin & Patterson, 1981). During adolescenece, rapid physiological changes, manifested primarily by acelerated growth and the development of secondary sex characteristics, occur (Coupey & Cohen, 1981). These pubertal changes cause adolescents to be preoccupied with their appearance and arouse interest in the opposite sex (Erikson, 1968). The chronic debilitating and progressively fatal disease, cystic fibrosis, which interferes with growth, sexual identity, and physical attractiveness can profoundly affect the emotional state of the adolescent experiencing such pubertal change and thus limit the successful completion of adolescent developmental tasks

and preparation for adulthood (Coupey & Cohen, 1981; Landon et al., 1980; Lewiston, 1980).

As these adolescents face both the challenges of adolescent development and management of their illness, the family also becomes markedly affected (Boyle et al., 1976; Hymovich, 1981). The ability of the family to utilize coping behaviors for the perceived stressors will significantly affect the health of the chronically ill member (Patterson & McCubbin, 1983).

Significance

Cystic fibrosis is transmitted as an autosomal recessive trait in one in every 1,500 to 2,000 caucasians (Warwick, 1980). In recent years, there has been an increase in survival rates for individuals with this disease (Blessing-Moore, 1979). Whereas, in 1966 the average age at death was 10.4 years, in 1972 it had increased to 18.1 years (Warwick, 1980). In 1974 (the most recent year for which statistics are available) there were 1,439 individuals, 45% of which were females over the age of 17, reported to have cystic fibrosis (Cohen, di Sant'Agnese, & Friedlander, 1980). Due to this improved survival rate, many females with cystic fibrosis are now adults capable of childbearing and childrearing.

It can be an overwhelming and sometimes impossible task for adolescents with this disease to successfully accomplish the complex process of maturation while

simultaneously coping with a severely debilitating and progressively fatal illness. Research has explored the stressors experienced by adolescents with cystic fibrosis (Landon et al., 1980; Leichtman & Friedman, 1975; Lewiston, 1980; Pinkerton, 1969; Rosenlund & Lustig, 1973; Wolfish & McLean, 1974) and of families with an adolescent with cystic fibrosis (Anderson, 1960; Burton, 1973; McCollum, 1971; Turk, 1964). Studies also have observed the negative coping behaviors utilized by adolescents with cystic fibrosis and their families (Allan, Townley, & Phelan, 1974; Gayton, Friedman, Tavormina, & Tucker, 1977; Lawler, Nakielry, & Wright, 1966; McCrae, 1974).

Evidence suggests there is improved management of care with increased physiological and psychological well-being in individuals who, together with their families, utilize adaptive coping behaviors (McCubbin et al., 1979; Patterson & McCubbin, 1983). The present study has attempted to examine the identified stressors and coping behaviors in managing cystic fibrosis by adolescents and their families.

CHAPTER TWO

REVIEW OF LITERATURE

Adolescent Development

Adolescence in Western culture is a stressful period (Daniel, 1977). During adolescence, rapid physiological changes, manifested primarily by accelerated growth and the development of secondary sex characteristics, occur (Coupey & Cohen, 1981). These pubertal changes cause adolescents to be preoccupied with their appearance and arouse interest in the opposite sex (Erikson, 1968).

Normal psychological maturation in adolescence involves the development of a self-concept from which a clear definition of one's identity and societal role can emerge (Owen & Matthew, 1980). Erikson (1968) has regarded the acquisition of a sense of identity as a vital task which each adolescent must master for preparation to adulthood. Cognitively, by age 15, adolescents are capable of formal operational thought and can reason deductively from their own hypotheses (Maier, 1967). However, full maturation of cognitive development is a partially learned phenomenon and is facilitated by exploration of personal, social, and ethical values with peers, parents, teachers, and by the development of one's intellect (Coupey & Cohen, 1981).

Erikson (1968) cited the developmental tasks of

adolescence as establishing identity and self-image, emancipation from the family, establishing an adult sexual role, and making career and vocational choices.

Stressors of Adolescents with a Chronic Illness

Adolescents with a chronic illness are in an especially vulnerable position. Not only must they master the developmental tasks of adolescence, but they also must manage the unique stressors imposed by their illness (Jelneck, 1977; Korsch, 1973; Lawson, 1977; Leichtman & Friedman, 1975).

Chronic illness can threaten physical integrity and one's efforts toward mastery and control of the environment. In early adolescence (ages 11 to 13), pubertal growth and awareness of self and others becomes prominent. Whereas, in mid adolescence (ages 14 to 16), chronic illness can hinder the transition from dependence to independence and alter one's body image and sexual identity, during late adolescence (ages 17 to adulthood), chronic illness can threaten identity formation and future career and marital planning (Smith & Deisler, 1979).

Often, chronic illness decreases stamina and may lead to a real or perceived inability to cope. Thus, the fragile self-image and self-esteem of the developing individual during adolescence is at high risk for disruption.

Stressors of Adolescents with Cystic Fibrosis

Cystic fibrosis creates all-encompassing challenges to the adolescent because of its unique and demanding stressors. Adolescents with this disease are affected with delayed and, often stunted, pubertal growth, sexual maturation, and stature which can profoundly affect their emotional state and identity formation (Boyle et al., 1976; Landon et al., 1980; Lewiston, 1980).

The restrictiveness and intense treatment regime imposed by cystic fibrosis creates dependence upon family members and limits social interaction at a time when independence and social activity is most important (Korsch, 1973). Frequently, these adolescents become fearful of pursuing peer relationships or engaging in social activities because of embarrassing pulmonary and gastrointestinal disturbances. Frequent and often prolonged absences due to hospitalization for recurring infections retard the acquisition of ongoing friendships and peer acceptance (Leichtman & Friedman, 1975; Pinkerton, 1969; Rosenlund & Lustig, 1973). Thus, adolescents with cystic fibrosis often are severely curtailed in their ability to interact with peers and miss the opportunity for intellectual stimulation from their social milieu (Coupey & Cohen, 1981).

Furthermore, their diminished physical strength limits their ability to be employed, which creates more dependence upon family members for financial and emotional support

(Rosenlund & Lustig, 1973; Teicher, 1969). Therefore, adolescents with cystic fibrosis can easily become frustrated in their quests for independence and normalcy.

Coping By Adolescents with Cystic Fibrosis

For management of the restrictiveness imposed by cystic fibrosis, its manifestations, and fatal prognosis, adolescents with this illness employ various coping mechanisms. Some of these mechanisms (projection, acting-out, and non-compliance) are clearly maladaptive, while others (intellectualization, displacement, and rationalization) can be healthy and adaptive (Coupey & Cohen, 1981; Smith & Deisher, 1979).

Several studies have documented maladaptive behaviors used by adolescents with cystic fibrosis. Responses to a self-image study indicated that adolescent males had an abnormal pattern of psychological adjustment when compared to published normative data for healthy adolescents (Landon et al., 1980). Bywater (1980) and Patterson (1980) noted a higher incidence of depression in these adolescents when compared with healthy subjects. Boyle, di Sant'Agnese, Sack, Millican, and Kulczycki (1976) explored the psychological impact of cystic fibrosis in a sample of 27 adolescents and young adults observing that 26% of the group felt isolated while 41% felt hostile toward themselves and their families. They also reported impaired emotional adjustment, anxiety, and depression and identified these

areas of stress: conflicting demands at home and anxiety toward body image and the future.

In contrast, a study compared the responses of 349 healthy adolescents to 168 adolescents with chronic or serious illness (23 subjects had cystic fibrosis, degree of symptomatology not stated) on standardized measures of trait anxiety, self-esteem, and perception of self-control over health and illness (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980). These findings were consistent with other researchers who report that objective measures have not evidenced psychopathology in chronically ill adolescents (Bedell, Giordani, & Amour, 1971; Zeltzer et al., 1980).

Bronheim and Kulczycki (1980) documented the following positive coping behaviors: relying on family for emotional and financial support, seeking peers for support and companionship, actively participating in their treatment regime, viewing physical setbacks as learning experiences, maintaining a sense of normalcy by continued achievement and productivity despite exacerbations and goal flexibility. Researchers Kulczycki, Leet, and Morrison (1979) and Strauss, Pederson, and Dudovitz (1978) identified the need for adolescents and young adults with cystic fibrosis to exert control in the management of their illness. Both healthy and chronically ill adolescents are in agreement that illness disrupts not only their lives in general, but

also their relations with peers, siblings, and parents (Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980).

Stressors of Parents of Adolescents with Cystic Fibrosis

The rapid physiological and psychological growth spurt of adolescence can alter familial structure, function, and stability. For example, parents must adapt to their adolescent's changing dimensions: forming peer and intimate relationships; and leaving home to pursue an education or gain vocational training (Boss, 1980).

In addition, the structure and function of the family can be affected by the unique stressors of cystic fibrosis. For instance, if the female parent remains unemployed to care for the chronically ill member, the family must adapt to the additional financial constraints and daily home care. Often, the working parent must reject job promotions and/or transfers due to continuous high stress levels within the family and the need for close availability of specialized health services and employee benefits which offer an affordable comprehensive health coverage.

Parents of adolescents with cystic fibrosis have reported difficulties in managing the illness. Not only does management employ a physically demanding and often costly treatment regime, but the debilitating and fatal component of the illness taxes the emotional resources of the family, limits family recreational activities, and

personal leisure time (Anderson, 1960; Burton, 1963; McCollum, 1971; Mattsson, 1972; Turk, 1964).

In a critical analysis of studies examining the familial stressors of cystic fibrosis, Frydman (1979) noted methodological inconsistencies with generalization from small sample sizes and an overemphasis on the negative consequences of the disease. He concurred with other researchers (Dennings, Gluckson, & Mohr, 1979) that cystic fibrosis consistently produced psychological and social problems in the patient, parent, and families. Patterson and McCubbin (1983) in a study of 100 families of children with cystic fibrosis noted lowered physiological well being in the ill member during familial stress pile-up. To date, no studies have addressed the stressors experienced by families with more than one sibling with cystic fibrosis, despite the high genetic possibility for such occurrence (one affected child out of four if both parents are carriers).

Coping by Parents of Adolescents with Cystic Fibrosis

For adaptation to these stressors, researchers have reported conflict suppression between family members, control, and low expressiveness in siblings (Bywater, 1980; Heideck, Wasserman, Mather, & Davis, 1982; Kulczycki et al., 1979; Swenden, Walsh, McDermott, Ford, & Kahn, 1974). Decreased communication and conflict between spouses over illness management as well as dependency on the

medical team for emotional and informational support has been noted (Allan, Townley, & Phelan, 1974; Lawler, Nakielry, & Wright, 1966). In a study of 38 families, Boyle et al. (1976) observed uninvolved, abusive, or absent participation by fathers. In a recent study researchers Tropauer, Franz, and Dilgard (1979) observed the maladaptive coping responses utilized by parents to be similarly expressed by the chronically ill member with cystic fibrosis.

Of the few studies which have focused on the positive aspects of familial response to stress, researchers McCubbin, McCubbin, Patterson, Cauble, Wilson, and Warwick (in press) noted significant improvement in pulmonary functioning of children with cystic fibrosis when parents utilized the adaptive coping behaviors of maintaining self-esteem and obtaining social support. Although these parents used similar coping patterns, the effects on family functioning were different. The mother's coping effort significantly related to promoting interpersonal relationships in the family, cohesiveness and expressiveness, while the father's was associated with both the interpersonal relationship with the family (cohesiveness and reducing conflict) and the system maintenance of the family (promoting organization) (McCubbin, Patterson, Cauble, Larsen, Comeau, & Skinner, 1981, p. 173).

Research on family coping has been extremely limited despite the large volume of literature which discusses the

cognitive psychological theories (Lazarus, 1966) and the sociological theories (Mechanic, 1970) of coping. Recent accumulating empirical evidence has linked coping to successful individual adjustment and has encouraged a shift toward measuring the family's adaptive response to stress rather than a problematic and dysfunctional approach to measuring the effect of stressor(s) (McCubbin, Patterson, Cauble, Larsen, Cameau, & Skinner, 1981).

Adolescents with cystic fibrosis and their families are in a vulnerable position. Continually each is presented with stressors imposed not only by the illness, but also by their developmental tasks and needs of daily functioning. This study directs attention toward identifying and measuring those behaviors found helpful in managing the illness.

CHAPTER THREE

METHODOLOGY

Overview

This exploratory study investigated the identified stressors and coping behaviors utilized by adolescents with cystic fibrosis and their families in managing the illness. Specifically, similarities and differences in responses of the adolescent, mother, and father to interview and self-report instruments were examined.

Sample

A convenience sample of 21 adolescents, 19 female parents, and 8 male parents from 19 families participated in the study. Two sampling plans were employed. Initially, adolescents and their parent(s) receiving care at a large university regional center for cystic fibrosis were asked to participate if the following criteria were met: adolescents aged 13 to 18 years; moderately symptomatic of cystic fibrosis; living with their parent(s); and either or both parent(s) willing to participate. It was anticipated that data would be collected from the adolescent and the parent(s) during a 1-hour meeting as part of their regular clinic visit. This plan did not work well.

Several difficulties were encountered in obtaining an adequate sample size. The clinic's directory was not current and some families obtained care at more than one

facility. The sample size was further limited by the specific requirements for Schwachman scoring,[1] the commuting distance for many of the families, and the high refusal rate of those who did qualify. Of the 57 families contacted, 24% refused to participate. Fifty percent did not wish to discuss the variables under study; the remaining 50% lacked interest.

As a result, the second plan was implemented to increase sample size with the following alterations in criteria. Adolescents aged 11 to 21 years were eligible if they had utilized the clinic within the past year; were patients of a local physician; or had resided with their parent(s) or legal guardian until 2 months prior to data collection. For those who cancelled the pre-scheduled meeting with the investigator during their regular clinic visit, completion of the data was made available by phone and/or by mail. To further accommodate the needs of the parents, those who commuted more than 100 miles to the clinic; visited it infrequently; or would not be attending the clinic during the 3-month period of data collection were visited at home or work by the investigator or were asked to complete the data by phone and/or mail.

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[1]Shwachman and Kulczycki (1979) categorized the severity of cystic fibrosis by Schwachman points--40 to 80 points indicated moderate symptomatology.

Sample Criteria

The following sample criteria were established as a result of extensive revision. Adolescents were eligible who were:

(1) aged 11 to 21 years;

(2) moderately symptomatic of cystic fibrosis;

(3) living with their parent(s) or legal guardian until 2 months prior to data collection;

(4) and utilizing the clinic or the services of a local physician within the past year.

A pool of 57 adolescents and their parent(s) who met these criteria were identified from clinic records and mailed an introductory packet. Of the selected sample, 38% could not be located or did not meet study criteria and 24% refused to participate. Thirty-eight percent did agree to participate and were divided into the following categories because of variation among participating subjects.

Group A consisted of 17 families comprising 17 adolescents with cystic fibrosis and their female parents. Subgroup A consisted of seven families comprising seven adolescents with cystic fibrosis and their male and female parents.

Group B consisted of two families. The members of one family involved two adolescent siblings with cystic fibrosis and the female parent. The members of the other family involved two

adolescent siblings with cystic fibrosis and the male and female parent (Table 1 & 2).

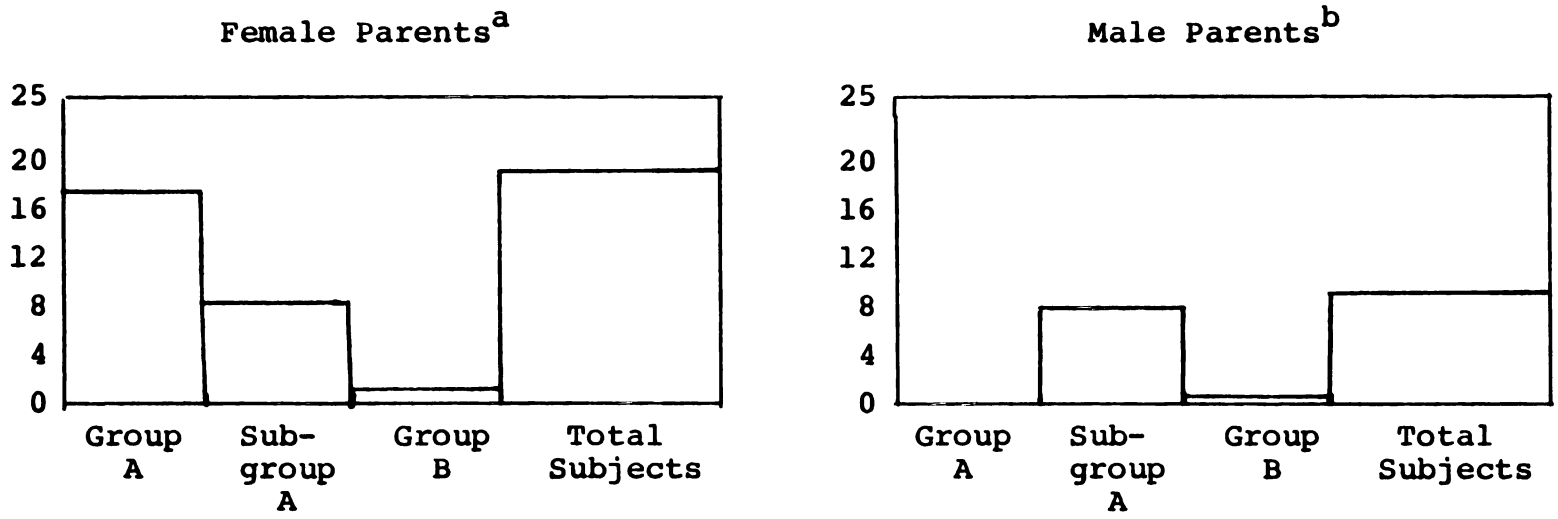
Sample Description

Nine male and 12 female adolescent subjects, ranging in age from 11 to 22 years, participated in the study. Ninety-five percent of the adolescents were enrolled at an age-appropriate educational level; for those adolescents attending secondary school the range was sixth to twelfth grade. The adolescents pursuing higher education attended either a local technical school or college. The type and extent of participation in the educational program selected was dependent on subject's age, interests, career goals, perceived support by the institution, severity of disease, and perceived degree of stress in managing the illness. Eighty-six percent of the adolescents lived at home; the remaining 14% had recently established residence at a local college dormitory for their freshman year.

Eight male parents, aged 30 to 49 years ($\bar{X}$ = 39), and 19 female parents, aged 30 to 50 years and over ($\bar{X}$ = 44), participated in the study. The educational level of male parents ranged from tenth grade to graduate school, those for female parents was tenth grade to college graduates. In each family with a male parent present, the parent was employed full-time; whereas for families with only a female parent 47% were employed full-time, 16% part-time, and 37%

Table 1

Parent Group and Subgroup Size



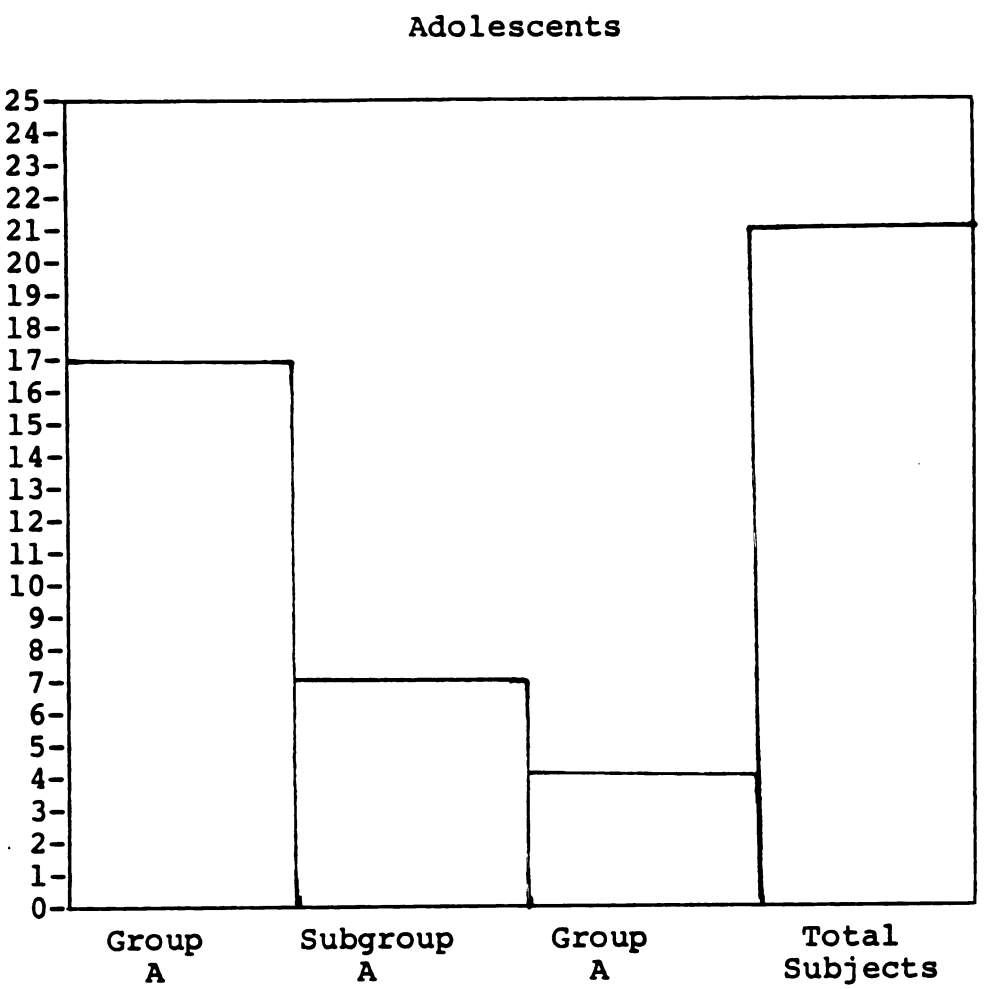
a. Female parent refers to the parent subjects whose relationship with the adolescent was either the mother, grandmother, adopted mother, or legal guardian.

b. Male parent refers to the parent subjects whose relationship with the adolescent was either the father, stepfather, adopted father, or partner to the other parent.

Group A consisted of 17 families comprising 17 adolescents with cystic fibrosis and their female parents.
Subgroup A consisted of seven families comprising seven adolescents with cystic fibrosis and their male and female parents.
Group B consisted of two families. The members of one family involved two adolescent siblings with cystic fibrosis and the female parent. The members of the other family involved two adolescent siblings with cystic fibrosis and the male and female parent.

Table 2

Adolescent Group and Subgroup Size



Group A consisted of 17 families comprising 17 adolescents with cystic fibrosis and their female parents.

Subgroup A consisted of seven families comprising seven adolescents with cystic fibrosis and their male and female parents.

Group B consisted of two families. The members of one family involved two adolescent siblings with cystic fibrosis and the female parent. The members of the other family involved two adolescent siblings with cystic fibrosis and the male and female parent.

not employed. Computed Hollingshead (1978) social status scores ranged from 19 to 66 ($\bar{X}$ = 46). A score of 8 to 19 represents the social strata of an unskilled laborer, 20 to 29 represents that of a machine operator, while 30 to 39 represents that of a skilled craftsman. Scores 40 to 54 categorize the social strata of a minor professional, and 55 to 66 categorizes that of a professional. Of the 19 families, 69% of the parents were married; 21% had been married previously; and 26% were either separated or divorced (Table 3).

Utilization of the clinic was variable. Twenty-five percent regularly attended the clinic for biannual or annual consultation and 10% inconsistently attended for consultation and for hospitalization. Two of the families were members of a health maintenance organization and personally sought additional consultation services from the regional clinic.

For some, an extensive commute was required. Fifty-five percent of the families resided within 30 miles of the clinic; 15% resided within 100 miles; 25% resided within the state but lived beyond 100 miles from the clinic; and 5% resided outside the state (Table 4). The family which resided outside the state traveled 650 miles to the clinic for biannual consultation.

Procedures in Data Collection

Data were collected over a 3-month period. Potential

Table 3

Demographic Description of Sample

Adolescents
Group A & B

	Male (n=9)		Female (n=12)	
	$\bar{X}$	Range	$\bar{X}$	Range
Age in Years	17	14 to 22	16	11 to 21
Educational Year Completed	11	7 to 14	10	5 to 12

Parents
Group A & B / Subgroup A

	Male (n=8)		Female (n=19)	
	$\bar{X}$	Range	$\bar{X}$	Range
Age in Years	39	30 to 49	44	30 to 50
Educational Year Completed	14	10 to 18	12	10 to 16
Family Social Status Score*	48	19 to 66	45	30 to 53

*Hollingshead Index (1978)

Table 4

Comparison of Site of Data Collection to Residence

Site of Data Collection	Distance of Residence from University				
University Setting	a	b	c	d	
During Clinical Visit	1				Adolescent
	2		1		Mother
					Father
During Hospitalization of Adolescent	3		1		Adolescent
	2				Mother
	2		1		Father
Without Clinic Visit or Hospitalization	2	1			Adolescent
	1	1			Mother
					Father
Home or Work Visit	1	2			Adolescent
	2	2			Mother
					Father
Phone Interview with Completion of Instruments By Mail		1	2	1	Adolescent
	2	1	3	1	Mother
					Father
Interview and Completion of Instruments By Mail	3	1	2		Adolescent
	1		1		Mother
	1	2	1	1	Father

a = 0-30 miles
b = 30-100 miles
c = beyond 100 miles, within state
d = beyond state

subjects were mailed a packet containing the introductory letter from the Acting Director of the Allergy and Pulmonary Service at the clinic, the introductory letter from the researcher, the consent form, and the Experimental Subjects Bill of Rights (Appendices A, B, C, D).

The researcher telephoned the parent(s) and adolescent 2 weeks later to discuss the study, answer any questions, and learn of their decision regarding participation. If the parent(s) and adolescent wished to participate, then a date and time was arranged for a meeting at the clinic. If this was inconvenient, then an alternate site (home or work) or alternate method of participation (phone and/or mail) was arranged. For example, subjects who resided more than 100 miles from the clinic, visited it on an infrequent basis, or would not be utilizing its services during the period of data collection were visited at home or work by the investigator or completed the data by phone and/or mail. If only one parent could attend the meeting and the other parent wished to participate, then the packet and parent instrument was mailed to the absent parent for completion (Table 4). Telephone confirmation was made approximately 1 week prior to the meeting. During the prearranged 1-hour meeting, the parent(s) completed the parent instrument while the researcher interviewed the adolescent. Then the adolescent completed the adolescent instrument while the researcher interviewed the parent(s).

Individual members of the family were interviewed separately unless a joint interview was requested. This occurred once.

Interviews

The interview questionnaires, entitled Identified Stressors of Adolescents with Cystic Fibrosis: Adolescent Questionnaire and Identified Stressors of Parents of Adolescents with Cystic Fibrosis: Parent Questionnaire, were designed by the researcher to elicit additional information about stressors imposed by cystic fibrosis and adolescent development. The questionnaires consisted of 13 identical semi-structured questions. They were examined by three nurse researchers, had theoretical documentation for subject content (McCubbin et al., 1979; Richardson & Friedman, 1974; Rodgers, Ferholt, & Cooper, 1974), and were pilot tested on three chronically ill adolescents and their parent(s) by the researcher. The completion time, between 15 and 45 minutes, was dependent upon the length of responses by the adolescent and parent subjects (Appendices G, H).

Instruments

Adolescent Coping Orientation for Problem Experiences (A-COPE) is a 95-item questionnaire designed to record the behaviors adolescents find helpful in managing problems or difficult situations (McCubbin & Patterson, 1981). The questionnaire instructs adolescents to decide how well the statements describe what they do to cope with

difficulties and tension and includes such items as: talking to a teacher or counselor about what bothers me, talking to my father about what bothers me, talking to a friend about how I feel, going shopping, eating, using drugs not prescribed by a doctor, smoking, getting angry and yelling at people, and letting off steam by complaining to my friends. Their responses were rated on a 5-point Likert scale with choices ranging from not at all to extremely well.

Factor structure with alpha reliabilities ranging from .50 to .76 was obtained from a sample of 467 adolescents from the categories labeled ventilation, emotional connections, low to high level activity, friendship, professional and spiritual support, avoidance, self-reliance and positive appraisal, family problem solving, relaxation, and humor (McCubbin & Patterson, 1983). A study is currently in progress to delineate norms for healthy and chronically ill adolescents (Patterson, 1983). Face validity of the items was established by independent judgments of adolescents, high school counselors, and teachers. Completion time was between 10 and 20 minutes for the adolescent subjects (Appendix E).

Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) is a 103-item instrument designed to measure nursing interventions for families with chronically ill children and to identify those at risk.

The substantive content was developed in response to questions: How do children with cystic fibrosis affect family developmental tasks? How do parents of chronically ill children cope with management of the illness (Hymovich, 1981)?

The instrument elicited information on the following areas of family development: demographic characteristics, health of family members, aspects of the ill child's development that require assistance, and support systems utilized. Questions directed at soliciting responses to behaviors utilized when upset with child's illness or with relationship with partner included crying, yelling, praying, drinking, or increasing activities. Parents were also asked to identify areas of concern associated with the child's illness and relationship with partner. Responses were measured using both Likert scales and yes/no categories.

Reliability was determined using a convenience sample of 29 parents ranging in age from 24 to 57 years ($\bar{X}$ = 34 years) representing all socioeconomic levels. Seventy-two percent of the families were intact; 28% contained one parent. Statistical analysis by the Laboratory of Educational Research Test revealed a Hoyt's coefficient of reliability ranging from .31 to .94. Frequencies were obtained by using the Statistical Package for the Social Sciences. Completion time was between 15 and 25 minutes

for the parent subjects (Appendix F).

Data Analyses

Constant comparative analyses of interview questionnaires for parents and adolescents was done to describe categories of stressors (Glaser & Strauss, 1967). Non-parametric analyses of mean scores from the 12 factors identified by McCubbin and Patterson (1983) from an earlier larger study of adolescents with cystic fibrosis reported helpfulness of coping behaviors utilized by adolescents. Differences in responses between male adolescents (n=8) and female adolescents (n=9) in Group A were also examined using the Mann Whitney Wilcoxen Sum Rank test. Mean scores and frequencies for concerns of mothers and fathers were identified. Agreement between mothers and fathers for managing the illness and in dealing with spousal relationships was reported by Spearman correlations.

CHAPTER FOUR

PRESENTATION AND ANALYSIS OF FINDINGS

Data obtained from interviews and self report instruments of 21 adolescents and their parents were analyzed according to methods described in Chapter Three. The following results are discussed: stressors of adolescents with cystic fibrosis, coping behaviors of adolescents with cystic fibrosis, stressors of parents of adolescents with cystic fibrosis, and coping behaviors of adolescents with cystic fibrosis.

Stressors of Adolescents with Cystic Fibrosis

In the analysis of interview data four categories of perceived stressors emerged: academic, social, and environmental difficulties and dissatisfaction with health problems. The category, academic difficulties, described stressors associated with school personnel who were perceived to be unaware of the adolescents' problems with managing the illness. Of particular concern for these adolescents was being able to complete required course work because of absences for illness.

The stressor, social difficulties, was associated with frequent prolonged absences, physical stigma, and illness prognosis that the adolescent perceived as impeding close friendships and intimate relationships with the opposite sex. The category, environmental

difficulties, described stressors associated with the restrictiveness which cystic fibrosis created on their lifestyle. For example, the adolescents who attended school had to obtain special parking privileges, and enroll in an adaptive physical education program in order to accommodate the limitations of their illness.

Dissatisfaction with health professionals was identified as a stressor by these adolescents who perceived that health providers failed to acknowledge their concerns and did not communicate at their level. The data presented in Table 6 discusses the specific issues related to these stressors and summarizes with selected quotations the responses of families with one adolescent (Group A, N=17) and families with two adolescents (Group B, N=4).

Table 5

Perceived Stressors by Adolescents with Cystic Fibrosis

Stressor One: Academic Difficulties

	Adolescent Responses	Related Issues	Supportive Quotes
I. Frequent and/or Prolonged Absences	1) Passive A) Minimize academic difficulties B) Accept poor grades C) Drop-out 2) Active A) Have parent and/or physician intervene B) Get home tutor C) Initiate communication with teacher(s) and counselor(s) D) Change student status from full-time to part-time	1) Missed course work not sent home unless requested by parent(s)	"Most definitely difficult. Everything gets screwed up when you're out 4 weeks out of 6, especially the first 4 weeks. It makes it hard to keep up with everything." "It's difficult...trying to make up missed work due to illness, having to drop a class because of being absent, having to carry supplies to and from class, and, the number of classes needed to be a full-time student."
		2) Limited or non-existent communication between school personnel	"The first year (seventh grade) I missed a lot. I really got behind. Made school really hard. I got no help until eighth grade so I dropped out and the next year they old me I could graduate (was in the ninth

Table 5 (continued)

Stressor 1: Academic Difficulties (continued)

Adolescent Responses	Related Issues	Supportive Quotes
		grade). Well I got mad. My mom agreed. I couldn't read at second grade level or do math or write. So I went to a special program there at school for the eighth grade--I learned more there than ever before. School has always been a pain in the neck. I never did like it."

Table 5 (continued)

Stressor 2: Social Difficulties

	Adolescent Responses	Related Issues	Supportive Quotes
I. Frequent and/or Prolonged Absences	1) Awareness of decreased consistency and continuity with peer relationships	1) Diminished peer relationships	"For some reason if you're not around people tend to forget who you are. Then you have to take time to explain why you were gone ...most definitely difficult." "Didn't have any friends [in high school]. Felt like an outsider in everything. Hard to make friends."
II. Physical Stigma of Illness	1) Embarrassed to be with peers	1) Altered identity	"I don't want people to think I'm special or different--think I'm a baby." "I'm always sick--when I cough it sounds like I'm choking. The kids are scared to be around me. I don't have a lot of friends." "I'm a super jock. I love tackle football and to wrestle. I should have been a boy. Everyone's

Table 5 (continued)

Stressor 2: Social Difficulties

	Adolescent Responses	Related Issues	Supportive Quotes
			afraid they'll break me--they can't."
III. Illness Disclosure/ Confidentiality	1) Learn discretion	1) Communication vs. Prognosis	"I have to be real careful how to tell him [present boyfriend]. In all the times past, once they've found out, they've split. Have to be careful that I tell him in the right, right way."
	2) Use social outlets and available persons for networking	1) small percent of teachers listen and allow for friendships	"My gym teacher is really caring and wants to know all about it [cystic fibrosis]. He wants to make sure what I'm doing is right -- and that it will work for me within my limitations."

Table 5 (continued)

Stressor 3: Environmental Difficulties

	Adolescent Responses	Related Issues	Supportive Quotes
I. Physical Limitations of Illness	1) Passive adaptation to limitations imposed by disease process	1) Non-compliance (get parking tickets, drop classes, use restroom only at home, refuse physical education)	"My high school counselor told my teachers--then my mom and I had a long talk with her and explained it and the teacher understood so it was okay to go to the bathroom."
	2) Active adaptation to limitations imposed by disease process	2) Manipulate or communicate with system to get special privileges (class excuses during coughing spells and gastrointestinal upsets, enroll in adaptive or specialized physical education, get home tutor, facilitate school memo on cystic fibrosis)	"At the beginning of a year a teacher signaled me out and started to give me a hard time. So I went to the school nurse and had her write a bulletin to all the teachers. Since that time there has been no problem."

Table 5 (continued)

Stressor 4: Dissatisfaction with Health Professionals

	Adolescent Responses	Related Issues	Supportive Quotes
I. Lack of Acknowledgment of Adolescents' Concerns with Appropriate Teaching	1) Communicate more with parents than adolescent	1) Perceived non-acceptance	"They need to tell patients more. Tell my mom something else than they tell me...There's so many things they don't tell me."
II. Not Communicating Adolescents' Level	1) Prefer buddy and not doctor-patient relationships	1) Role incongruity	"I liked Dr. K...he was new...so I had to tell him things about how to do it. It gave me a good feeling ...we became good friends ...not doctor-patient sort of things, just buddies. He'd come into my hospital room and we'd play chess together."
	2) Don't listen to what I want	1) Lack of control	"I don't like it when they play around with the meds."
		2) Perceived unconcern	"Yeh, they always talk superficial--always on this high level. Talk in these medical terms. I wish they'd say it in English.

Table 5 (continued)

Stressor 4: Dissatisfaction with Health Professionals

	Adolescent Responses	Related Issues	Supportive Quotes
			I always want to say ok, ok I'll do it--but why do I feel so cruddy? They tell me in medical terms. I wish they'd say it all in English. I'm really concerned about my appearance. I'm so skinny but they won't tell me anything."
III. Socialization not Encouraged	1) Don't promote socialization for acceptance of illness, peer identity, and support	1) Social networking by peers	"Need more groups together. Explain more about cystic fibrosis--like I don't know about Pseudomonas.[1] I just found out at last hospitalization that I had it and was resistant."
			"The social aspects have the greatest effect...like workshops or group meetings are important...learning how to deal with the illness. When you're a teenager your peer supports increase. It's important how you deal with that the rest of your life."

[1]Pseudomonas is a bacterial infection which can be resistant to extensive antibiotic therapy.

Coping Behaviors of Adolescents with Cystic Fibrosis

Twelve factors were determined from the A-COPE questionnaire and Table 6 reports the alpha reliability of each factor and the associated behaviors for this study (McCubbin & Patterson, 1983). These factors were utilized in this current exploratory study of coping behaviors in managing cystic fibrosis and dealing with adolescence.

Non-parametric analyses of the 12 factors were done on adolescents in Group A (N=17) using the Statistical Package for Social Sciences Program. Table 7 documents the significant differences in mean scores for each factor. As shown in this table, the adolescents rated low level activity as the most helpful coping factor. The behaviors which comprised this factor, sleeping, watching TV or movies, playing video games, and reading, were perceived as most helpful in managing cystic fibrosis and with the day to day issues of adolescence.

The adolescents also reported emotional connections, self-reliance and positive appraisal, and ventilation as helpful coping factors. Humor and spiritual and close friendship support were rated as minimally helpful. Professional support was rated as least helpful (Table 7).

Differences in responses between the male adolescents (N=8) and female adolescents (N=9) in Group A were also examined using the Mann Whitney Wilcoxon Sum Rank Test. No significant differences in scores for each factor

Table 6

Description of Factor Structure

	Coping Factor with Description of Behaviors	Alpha Reliability
I.	Ventilation	
	Q.33 Get angry and yell	.75
	Q.42,79 Let off steam by complaining to friends and family members	
II.	Low Level Activity	.75
	Q.22 Sleep	
	Q.19,36 Watch TV or movies	
	Q.2 Read	
	Q.37 Play video games	
III.	Self-Reliance and Positive Appraisal	.69
	Q.46 Make own decisions	
	Q.65 Organize life	
	Q.32 Deal with problems by self	
IV.	Emotional Connections	.75
	Q.1 Talk with friends about feelings	
	Q.50 Cry	
V.	Family Problem Solving	.75
	Q.10,14,20 Talk with father, mother, brother(s), or sister(s)	
	Q.16 Participate in family activities	
VI.	Passive Problem Solving; Avoidance	.71
	Q.15 Smoke	
	Q.21 Drink alcohol	
	Q.13 Use non-prescribed drugs	
VII.	Spiritual Support	.72
	Q.17 Pray	
	Q.53 Go to church	
	Q.8 Talk to minister	
VIII.	Friendship Support	.76
	Q.35 A boyfriend or girlfriend	
	Q.85 Closeness with someone you care about	

Table 6 (continued)

	Coping Factor with Description of Behaviors	Alpha Reliability
IX.	Professional Support Q.80,6 Counsel with school or health professional	.50
X.	High Level Activity Q.8 Strenuous physical activity Q.57 Self-improvement Q.11,40 Extracurricular activities	.67
XI.	Humor Q.59 Joke Q.34 Make light of situation	.72
XII.	Relaxation Q.76 Daydream Q.4 Listen to music Q.9 Eat food	.60

(A-COPE, McCubbin & Patterson, personal communication, 1983)

Table 7

Mean Scores for Adolescents' Reports of Helpfulness of Coping Behaviors
Group A N=17

Coping Factor	$\bar{X}$	S.D.	Range
Low Level Activity	26.67	6.32	18 to 36
Emotional Connections	20.93	5.71	12 to 30
Self-Reliance and Positive Appraisal	19.93	5.20	11 to 28
Ventilation	16.00	5.79	7 to 30
Family Problem Solving	15.88	6.27	6 to 27
High Level Activity	13.50	3.35	8 to 19
Relaxation	13.00	3.56	8 to 20
Passive Problem Solving: Avoidance	8.80	2.01	5 to 12
Humor	6.75	2.35	2 to 10
Spiritual Support	6.31	3.20	3 to 11
Close Friendship Support	6.20	3.43	2 to 10
Professional Support	3.75	2.49	2 to 10

between the male and female adolescents were determined. Factor correlations indicated no significant differences.

Stressors of Parents of Adolescents with Cystic Fibrosis

In the analysis of interview data, the following categories of perceived parental stressors emerged: familial and educational difficulties and management of the illness by health professionals. The stressor, familial difficulties, was the most often reported stressor. It consisted of issues regarding noninvolvement of spouse or conflict with spouse concerning illness management. For example, parents reported being dissatisfied with spousal and parental roles and perceived having a lack of communication with spouse.

Difficulties with school personnel were also identified as stressors to parents. The primary concern related to problems incurred with prolonged, frequent absences of their child. They perceived that teachers did not understand the disease process and, thus, were reluctant to either alter course requirements or send home assignments during absences.

The stressor, management of the illness by health professionals, encompassed parental perceptions that health providers were reluctant to discuss either the long term consequences or the supportive needs essential for better management of the illness. Parents also reported being concerned about the large number of health professionals

and school personnel who lacked information about the disease process and management. The data presented in Table 8 describes specific issues related to each of these stressors and summarizes the selected responses of female parents (Groups A & B, N=17) and male parents (Subgroup A & Group B, N=6).

Table 8

Perceived Stressors by Parents of Adolescents with Cystic Fibrosis

Stressor 1: Familial Difficulties

	Parent Responses	Related Issues	Supportive Quotes
I. Stressors and Management of Cystic Fibrosis	1) Job limits spousal support	1) Spousal uninvolvement with illness management--perceived as lack of support	"As much as time allows he is available. He supports me 100%."[a]
			"Has such a limited amount of time. Wish was more supportive of me--more sensitive to my needs. He's never available to take me to the doctors or anywhere else."[a]
			"He does what he can. Works long hours. Is as involved as can be."[a]
	2) Management of illness and perceived stressors create spousal conflict	1) Unresolved conflict	"We were divorced over her illness. He couldn't accept it and still can't. If she gets real sick he goes off by himself--he just can't handle it."[a]
		2) Spousal dissatisfaction with role expectations	"Since we've been back together--it's been mostly me--a solo performance."[a]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 1: Familial Difficulties (continued)

Parent Responses	Related Issues	Supportive Quotes
	3) Blocked or non-existent communication	"Used to be involved. Now don't even want him around. He took off years ago... Never goes to see him at the hospital."[a]
	4) Distorted concepts of disease process	"He's had a hard time accepting the disease. Has been a source of conflict between my husband and I. He says a diet will cure."[a]
1) Limitations of illness restrict progression through tasks of adolescence to adulthood	1) Social networking	"He's more family dependent than his brother [17 years] who doesn't have cystic fibrosis. 4-H [family very active] gave him an extended family where he could be himself. Don't know how stunted his development could have been without 4-H--until high school he was a total misfit."[a]
	2) Acceptance/ realistic expectations	"He wants to be more independent than he is. He's preoccupied with trying to find some sort of way to earn money. School is not

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 1: Familial Difficulties (continued)

Parent Responses	Related Issues	Supportive Quotes
		a money making business. We certainly have made no requests of him to find an occupation and make money."[b]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 2: Educational Difficulties

	Parent Responses	Related Issues	Supportive Quotes
I. Frequent and/or Prolonged Absences	1) Completion of course work requires cooperation by school personnel	1) Difficult to receive assistance from school during students' frequent absenteeism	"His grades are down with frequent absences. He gets behind academically when hospitalized. It shows on his 6 week progress report."[b]
			"There have been periods with poor grades. Absenteeism has been a problem."[b]
		2) Teachers would not send assignments unless specifically requested	"They're poor at sending out assignments. We communicate with them the extent of the illness."[a]
			"During illness we need the school's cooperation to get homework. Must ask for it specifically. They can distort things. We want normal treatment of our children and discuss with their teachers if they can't handle their classwork."[b]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 1: Educational Difficulties (continued)

	Parent Responses	Related Issues	Supportive Quotes
II. Limited Understanding/Acknowledgment of Disease Process	1) Response by school personnel inappropriate or lacking	1) Cystic Fibrosis pamphlet useful means of communicating information about disease process	"Would say they are interested. I usually give them the cystic fibrosis pamphlet...their biggest question is can she do everything?"[a]
		2) Annual parent-teacher conferences excellent opportunity to discuss management	"There have been social problems with the teachers. His elementary teachers wanted him to take athletic lessons so he'd blend better."[a]
		3) Limited funding has affected resources, consistency in responses by school nurses, counselors, and teachers	"A lot of teachers never heard of it. Finally had to get a school nurse involved to teach teachers--many nurses don't even know."[a]
	2) Special privileges needed for frequent respiratory and gastrointestinal disturbances	1) Embarrassment and frequency of foul-smelling stools and coughing spells necessitated sensitivity to students' needs	"It's just been making them aware that if she does have a coughing spell she shouldn't have to wait to ask to be excused but could just leave. When she was younger and would have to

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 2: Educational Difficulties (continued)

	Parent Responses	Related Issues	Supportive Quotes
			go to the bathroom it was real important that she go right then."[a]
	3) Limitations imposed by disease frequently hindered completion of course work	1) Hardships inflicted because of inflexible expectations	"One teacher gave her a hard time. She knew she had cystic fibrosis but wouldn't bend the rules... It made her spring very trying and difficult."[a]
III. Inconsistent Involvement/ Response by School Personnel	1) Interest displayed by school personnel affected students' school appreciation	1) Academic/social climate affected students' response	"The school situation kept getting worse...There were years when he wouldn't even go...Sometimes he would have an understanding teacher, sometimes not."[a]
			"Had no sensitivity. Volunteered nothing or expressed any interest."[a]
			"A very negative experience school was. Now would never go back."
	2) Socialization toward normalcy		"They [school personnel] wanted to baby him and treat him like he had a handicap. Thank God he's not using it

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 2: Educational Difficulties (continued)

Parent Responses	Related Issues	Supportive Quotes
		as a crutch."[a]
		"We stress we wanted her treated as normal."[a]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 3: Management By Health Professionals

	Parent Responses	Related Issues	Supportive Quotes
I. Prolonged Life Expectancy	1) Reluctance to discuss long term consequences and management of disease	1) Diminished control with unexpected complications	"I like to plan and be prepared. I don't like surprises. It's difficult not to have something to plan for."[a]
		2) Need for birth control and genetic counseling	"Her hemorrhage was a total surprise. We weren't aware it would happen. It scared us to death. We were disgusted they never told us it would happen."[a]
			"There is a time for parental counseling that doesn't include the kid and the guilt number that you're protecting him."[b]
			"...Are males sterile? I heard that 12 years ago. Are females sterile?"[a]
			"Genetic counseling for everyone--are there adult and child carriers for cystic fibrosis? What are her chances for having a child with cystic fibrosis?"[a]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 3: Management By Health Professionals (continued)

Parent Responses	Related Issues	Supportive Quotes
	3) Questions not answered sufficiently	"I have had to press the point in order to get answers...I don't know if I always believe them, but it was a rational explanation I could give my son."[b]
	4) Constant change in treatment modalities	"There have been so many recent changes in the past years--you get the feeling of being a guinea pig."[b]
2) Ambiguity by health professionals over benefit of support groups		"Our physician has always encouraged us not to handicap ourselves mentally. That's why we didn't belong to any of the support groups...Maybe we've missed out because we supported ourselves...you're going to dwell on the disease if you join a club."[a]
3) Lack of awareness by health professionals and community for cystic fibrosis	1) Misdiagnosis/ mismanagement	"He wasn't diagnosed until age 1½. Nobody knew what it was. It finally got so bad--I ran out of money--He had been so sick every month of his life."[a]

a = female parent responses
b = male parent responses

Table 8 (continued)

Stressor 3: Management By Health Professionals (continued)

Parent Responses	Related Issues	Supportive Quotes
		"There needs to be an increased awareness by people of cystic fibrosis."[a]
4) Hospitalization promotes teaching and compliance	1) Peer pressure/ identity	"Hospitalization with other cystic fibrosis adolescents of same sex and same age effective for teaching instruction. We've been trying to get him to do things but it isn't until he's hospitalized and his friends say it works--that he does it. It's like a big brother/big sister thing. There's peer pressure and peer identity."[b]
	2) Availability	"Respiratory therapists are there 4 times a day and have time to sit around and watch T.V. and be friendly. Nurses are busy. Respirating therapists aren't that busy--they spend time with the patients and appear more relaxed. They can be helpful."[b]

Coping Behaviors of Parents of Adolescents with Cystic Fibrosis

Correlations of the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) using the Statistical Package for the Social Sciences Program in order to examine coping behaviors utilized in managing the illness and in dealing with spousal relationships. There was a significant correlation between mothers' and fathers' reports of change in spousal relationships since diagnosis of their child's illness (r=0.88, p=.02). However, female parents expressed greater dissatisfaction with spousal interactions than male parents (r=0.73, p=.05). Associations were also found in the following behaviors used when either the male or female parents was with their partner: crying, increasing activities, ignoring or trying to forget, hiding feelings, smoking, yelling, exercise, and praying (r=0.84, p=.02).

Frequencies of fathers' and mothers' concerns in managing the adolescent's illness are reported in Table 9. Total agreement was reported by parents for making their adolescent comfortable or happy (r=1.0, p=.002). Aside from the behaviors, asking for help and yelling or slamming doors, which were used more frequently by female parents generalized agreement was noted in coping behaviors found helpful when the adolescents' condition worsens (Table 10). The behaviors found most helpful to parents--praying,

Table 9

Frequencies of Concerns Expressed by Parents in Managing the Illness

Concerns	Female Parents Group A N=17	Male Parents Subgroup A N=6
Wondering what my child's future will be	82%	66%
Feeling worn out	76%	50%
Making my adolescent comfortable or happy	70%	66%
Caring for my child in the best way	64%	66%
Worrying about my responsibility of caring for my adolescent	64%	66%
Extra demands on time	58%	50%
Doing activities as a family	58%	33%
Enough insurance for child care expenses	53%	16%
Traveling too far for medical help	47%	50%
Adequate community agencies for care of my adolescent	41%	33%
Enough fun and relaxation as I would like	41%	16%

Table 10

Frequencies of Coping Behaviors Utilized by Parents when Adolescents' Condition Worsens

Behaviors	Female Parents Group A N=17	Male Parents Subgroup A N=6
Pray	88%	66%
Talk with someone	82%	50%
Cry	76%	50%
Busy self with other things	70%	66%
Ask for help	70%	16%
Exercise	64%	33%
Hide feelings	58%	50%
Ignore/try to forget	53%	33%
Get away	47%	33%
Yell/Scream/Slam doors	47%	16%
Take more alcohol	35%	16%
Take more medicine	30%	16%
Smoke more	12%	33%

crying, talking, and increasing one's activities--correlated to those reported as most helpful for adolescents with the exception of praying.

CHAPTER FIVE

CONCLUSIONS AND DISCUSSION

Discussion

Stressors of Adolescents with Cystic Fibrosis.

Adolescents identified day to day stressors in areas related to adolescent development, education, and illness management. The stressors related to adolescent development support the findings of recent studies (Boyle, di Sant'Agnese, Sack, Millican, & Kulczycki, 1976; Landon et al., 1980; Tropauer, 1970).

The stressors associated with education and illness management were suggested by the adolescents' responses to the interview questionnaire which described their perceived disinterest by school personnel, difficulty in communicating with health providers, and a lack of control in managing their illness.

Significant relationships were found between adolescent responses to the interview questionnaire and to the self-report instrument, A-COPE. For example, in the interview data adolescents perceived academic difficulties and dissatisfaction with health providers as major stressors. Their response to A-COPE factor IX, professional support, further indicated this to be least helpful to adolescents in managing their illness.

The interview data also identified the hardships in

maintaining close friendships and securing intimate relationships with others inherent in the stressor labeled socail difficulties which was also supported by the finding that A-COPE factor VIII, close friendship support, was rated minimally helpful for managing the illness.

Coping Behaviors of Adolescents with Cystic Fibrosis. The coping behaviors found helpful for adolescents with cystic fibrosis were reported by using the factors of A-COPE determined in an earlier and larger study (McCubbin & Patterson, 1983). Although the interview data supported the findings of A-COPE, norms for comparison of responses to healthy and other chronically ill adolescents were not available (Patterson, 1983).

Since the A-COPE was a socialization measure of helpful action-oriented behaviors for managing adolescence and stressful life experiences correlations could not be done with recent studies which measured psychopathology and psychomaladjustment by adolescents with cystic fibrosis (Boyle, di Sant'Agnese, Sack, Millican, & Kulczycki, 1976; Bywater, 1980; Landon et al., 1980; Patterson, 1980). However, there was agreement between findings reported in interview data and those of researchers Bronheim and Kulczycki (1980), Kulczycki, Leet, and Morrison (1979), and Strauss, Pederson, and Dudovitz (1978). Behaviors identified as most helpful in these studies were reliance on family for emotional and financial support, seeking peers for support and companionship, maintaining a sense of normalcy by continued achievement

and productivity despite exacerbations, and exerting control in managing the illness.

Stressors of Parents of Adolescents with Cystic Fibrosis. Parents identified day to day stressors in areas related to spousal involvement, education of their adolescent(s), and management of the illness. The stressors related to spousal involvement support the findings of previous studies (Boyle, di Sant'Agnese, Sack, Millican, & Kulczycki, 1976; Tropauer et al., 1970) reporting absent or uninvolved participation by fathers and stressful interpersonal spousal relationships. The stressors associated with education and illness management were suggested by parent responses to the interview questionnaire. The data identified parental perceptions that school personnel were unaware of the disease process and, thus, appeared inflexible, while health providers were reluctant to discuss either the long term consequences or the supportive needs essential for better management of the child's illness.

Significant relationships were found between responses to the self-report instrument, CICI:PQ, and to the interview questionnaire. For example, findings from the CICI:PQ confirmed spousal dissatisfaction and a change in spousal relationship since diagnosis. This data also agreed with the interview questionnaire, stressor one, familial difficulties, which identified spousal noninvolvement, a lack

of communication with partner, and conflict with spouse over illness management as major concerns. Comparison of responses by parents also suggested that management of the illness affected time alone with spouse and communication patterns.

Coping Behaviors of Parents of Adolescents with Cystic Fibrosis. The coping behaviors found helpful for managing the illness were reported from analyses of the CICI:PQ. Agreement was noted by spouses for such behaviors as crying, increased activity, ignoring or trying to forget, hiding feelings, smoking, yelling, exercise, and prayer. The female parent reported using the behaviors asking for help and yelling more than the male parent. Highest agreement by parents was noted for the concern, making our adolescent comfortable or happy. The findings support those of other studies which report a heightened use of either adaptive or maladaptive coping behaviors by parents of children or adolescents with a chronic illness (Boyle, di Sant'Agnese, Sack, Millican, & Kulczycki, 1976; Hymovich, 1980; Patterson & McCubbin 1983; Tropauer et al., 1970).

Conclusion

This study examined the stressors and coping behaviors of adolescents with cystic fibrosis and their families. An effort has been made to apply past research and family stress theory to adolescence, family development, and

coping. As a fatal debilitating chronic illness, cystic fibrosis affects family functioning and the adolescent's mastery of developmental tasks.

Adolescents experienced stressors related to their social and academic milieu, and in communicating with health providers. The most helpful coping behaviors for managing their illness included low level activity behaviors such as sleeping, watching TV or movies, playing video games, and reading appropriate to the physical disabilities of their disease. Indeed, it is suggested that these non-physical behaviors are most beneficial because of the restrictiveness of the illness.

On the other hand, parents of these ill adolescents experienced stressors related to spousal involvement, educational difficulties of their adolescent, and illness management. The clearest stressor to emerge for parents was lack of involvement by spouse for managing the illness. The coping behaviors used by parents were crying, increasing activities, ignoring or trying to forget, hiding feelings, smoking, yelling, exercise, and praying. There was noticeable agreement by spouses for the concern, making our child comfortable or happy.

The result of the investigation strengthens recent studies examining coping as an integral part of family stress theory by providing a description of coping behaviors utilized in managing cystic fibrosis. The outcome

of this study suggests that family stress research should continue to examine more rigorous methods for measuring individual and family system variables.

Limitations of the Study

The three problem areas addressed--study design, sampling, methodology, and analyses--suggest that the findings of this exploratory study be interpreted cautiously.

Study design. The sample contained several variations in family composition that seriously affected data analyses. The male parent was asked to participate in order to provide an accurate representation of perceived stressors and coping behaviors by spouses. Unfortunately, only six fathers participated which seriously restricted analyses examining spousal agreement.

Another variation was families with two adolescents with cystic fibrosis who met study criteria. Analyses was also limited in this group because of the independent nature of the sample. A similar problem occurred in a larger study of families with a member with cystic fibrosis (Patterson & McCubbin, 1983). Their sample contained the same percent (10%) of families with more than one member with cystic fibrosis.

Sampling. Numerous difficulties were encountered in obtaining an adequate sample size. An extended time period was needed for contacting subjects since the

clinic's directory was not complete. Some families obtained care at other than one facility or commuted long distances for treatment; these families used the clinic infrequently.

The study criteria which was revised to expand the sample size effected methodology. For example, the adolescent interview questionnaire had to be adjusted to include adolescents from 11 to 21 years who fit into stages of early, middle, and late developmental stages. Also, subjects' responses to the interview questionnaire were variable depending on site and degree of privacy. For example, more spontaneous data were obtained when subjects were interviewed in person and privately than when interviewed in a group, by phone, or by mail.

Methodology. The parent self-report instrument, CICI:PQ, was chosen because it attempted to measure nursing interventions for families of chronically ill children. Coping was broadly operationalized to describe what one does to manage problems faced in raising chronically ill children (Hymovich, 1981, p. 72); other variables were included that were not pertinent to the scope of this study.

Further difficulties were encountered during administration of the CICI:PQ instrument. Parents frequently reported incorrect responses or missed items due to misreading the directions or individual questions. There were

numerous complaints about the amount of time required to complete the instrument, usually 25 minutes.

The adolescent self-report instrument, A-COPE, was chosen as it identified behaviors found helpful by adolescents for managing difficult life situations and adolescence. Several difficulties were experienced during administration. Without careful instruction, the adolescents misinterpreted the directions to mean behaviors I like to do rather than behaviors which help in managing the illness. Frequently the adolescents aged 11 to 15 needed clarification of the terminology.

Data analyses. Data analyses were complicated by several factors related to the CICI:PQ and A-COPE self-report instruments. The scoring instructions of the CICI:PQ did not address the needs of this study due to the broad scope of variables addressed. The varying Likert scales and yes/no categories made computer coding complex. Also, the variables addressed did not correlate with those of the A-COPE, therefore, agreement between parent and adolescent responses could not be obtained.

Analyses of the A-COPE was limited to the 12 factor groups as norms from recent larger samples on healthy and chronically ill adolescents were unavailable (Patterson, 1983). Therefore, there was not comparison of responses to other adolescents.

Future Research

In order to incorporate the findings of this exploratory research on a family's coping responses to the stress of their adolescent with chronic illness future research should focus on spousal interaction and stress pile-up. This small sample as well as other studies (Hymovich, 1980; Patterson & McCubbin ,1983) indicates that marital breakups occur in such families and the disease process appears to be related to this problem. Tools which specifically operationalize coping, methodology which addresses means for analyzing family responses and the inter-relationship between members are necessary to validate the needs of these individuals.

Clinical Significance

The increasing life expectancy of those with cystic fibrosis is taxing available health services. Not only do these individuals require extensive medical care, but they and their families require supportive services for management of the illness. Adolescents with a debilitating chronic illness face mastery of their developmental tasks for preparation to adulthood. Frequently, if the adolescents' educational and social milieu does not accommodate the needs of their illness, maladaptive coping responses and turmoil result.

A major difficulty experienced by these families related to continuity of health services. Because of the

specialized services required, some commuted extensive distances while others utilized a combination of agencies for care. Both parent(s) and adolescents expressed a desire to be fully involved in managing the illness and felt frustrated with limited responses to questions.

Another difficulty experienced was related to the educational system. Repeatedly, parents requested normalization of their adolescents, while school personnel maintained varying degrees of interest and understanding for the disease process. Since these adolescents maintained an age-appropriate educational level, promotion of adaptive means for better accommodating their needs seems vital.

It was reported that family inter-relationships were often strained due to the day to day stressors in the managment of the illness. Male parents voiced either a lack of interest or frustration at their lack of time. Female parents frequently reported non-supportive, uninvolved spouses. Adolescents expressed a need for control in managing their illness, and yet, recognized their dependence upon family members for assistance.

Nurses and other health providers are in a strategic position to intervene after assessing needs and potential problem areas within these families. Assessment criteria and tools must be established which specifically measure the unique stressors of cystic fibrosis.

Appendix A

Children's Hospital at Stanford
520 Willow Road
Palo Alto, CA 94304
October 5, 1982

Dear _____,

This is to introduce Ms. Anne C. Patton, a graduate nursing student at the University of California, San Francisco, who is conducting research on the effect of chronic illness on adolescents and their families.

Ms. Patton has provided me with the details of her research and I have granted her permission to contact you. You and your son or daughter's decision to participate is entirely voluntary and will have no effect on the care you receive at this hospital.

I appreciate your consideration of this research study.

Sincerely,

Richard B. Moss, M.D.
Acting Chief
Allergy and Pulmonary Disease Service

Appendix B

137 Berenda
South San Francisco, CA 94080
October 5, 1982

Dear Parent,

Dr. Richard Moss, Acting Director of the Pediatric Allergy and Pulmonary Service at Children's Hospital at Stanford, has given me permission to contact you. I have attached a copy of his letter as well as a copy of the consent form explaining this study.

I am a graduate nursing student at the University of California, San Francisco and am studying the effect of chronic illness on adolescents and their families.

I would like to ask for you and your son or daughter's participation in this work. I will be contacting you within the next two weeks to discuss this study with you. If you would like to participate, then I will arrange to meet with you during your visit to the Allergy and Pulmonary Clinic.

If you have any questions about my work or your involvement in it, please call me collect at (415) 872-3654. Your participation in this study will add to the current knowledge on chronic illness.

Sincerely,

Anne C. Patton

Ms. Anne C. Patton

cc: Dr. Richard Moss

Appendix C

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO ACT AS A RESEARCH SUBJECT

Study No._____

"Adolescents with Cystic Fibrosis and Their Families: Normative and Situational Stressors." A study conducted by Anne C. Patton, R.N., B.S.N., student, University of California, San Francisco, School of Nursing.

You and your spouse and your son or daughter with cystic fibrosis are invited to participate in this study. The purpose of this study is to learn more about the stressors incurred and coping strategies utilized by adolescents with cystic fibrosis and their families in order that health professionals can provide more effective care. Your participation will involve one meeting either before or after your appointment with the Allergy and Pulmonary Clinic at Children's Hospital at Stanford. During the meeting I will conduct a short interview with you and give you a questionnaire to complete. This meeting will be arranged and confirmed by telephone and will last approximately one hour. If your spouse cannot be present for the meeting but would like to participate, then after our meeting I will give you a copy of the consent form, interview form, and questionnaire for completion and return by mail.

Participation in this study is entirely voluntary. Refusal to participate or withdrawal from this study at any time will not affect your present or future health care at Children's Hospital at Stanford.

You will not receive any compensation or any direct benefit from participation in this study other than the satisfaction of discussing your concerns related to chronic illness.

Every effort will be made to maintain your confidentiality and anonymity. Your name will not appear on either the interview form or questionnaire. All such forms will be numerically coded. Other researchers may use the responses for similar areas of study but none will be given your name without your permission.

No data will be obtained from your medical record.

If you feel any of the items asked during the interview or on the questionnaire are too personal, you may refuse to answer them.

This information has been explained clearly to me. I have been given a copy of this consent form and the letter from Dr. Richard Moss, Acting Director of the Allergy and Pulmonary Clinic at Children's Hospital at Stanford. If I have any questions I may phone either Anne C. Patton at (415) 872-3654 or Dr. Richard Moss at (415) 327-4800. By signing this consent, I agree to participate in this study.

Signature of Adolescent_____ Date_____

Signature of Parent(s)_____ Date_____

Appendix D

Experimental Subject's Bill of Rights

Persons who participate in a medical experiment are entitled to certain rights. These rights include but are not limited to the subject's right to: be informed of the nature and purpose of the experiment; be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized; be given a description of any attendant discomforts and risks reasonably to be expected; be given an explanation of any benefits to the subject reasonably to be expected, if applicable; be given a disclosure of any appropriate alternatives, drugs, or devices that might be advantageous to the subject, their relative risks and benefits; be informed of the avenues of medical treatment, if any, available to the subject after the experiment if complications should arise; be given an opportunity to ask any questions concerning the experiment or the procedures involved; be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice; be given a copy of the signed and dated consent form; and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

In the event of physical injury that arises solely out of the negligence of the Stanford University Medical Center or its staff in this study, reimbursement for expenses incurred for necessary medical treatment and hospitalization is available. For further information, please call 497-5244 or write the Medical Center Committee for the Protection of Human Subjects at 851 Welch Road, Room 115, Palo Alto, California, 94304. In addition, if you are not satisfied with the manner in which this study is being conducted, you may report any complaints to the same telephone number and address.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, AND THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED. A COPY OF THIS FORM IS AVAILABLE TO YOU UPON REQUEST.

_____ Date_____
Signature

_____
Signature of Investigator or Witness

Appendix E

University of Minnesota
Family Social Science
290 McNeal Hall
St Paul MN 55108

Family Health Program
FORM A
1981

A-COPE

ADOLESCENT – COPING ORIENTATION FOR PROBLEM EXPERIENCES

Joan M. Patterson Hamilton I. McCubbin

PURPOSE

A-COPE is designed to record the behaviors adolescents find helpful to them in managing problems or difficult situations which happen to them or members of their families. Coping is defined as individual or group behavior used to manage the hardships and relieve the discomfort associated with life changes or difficult life events.

DIRECTIONS

Read each statement on the following pages which describes a behavior for coping with difficulties and tension.

Decide how well each statement describes WHAT YOU DO to cope with difficulties and tension. Choose one of the following responses:

1. NOT AT ALL 2. SLIGHTLY 3. SOMEWHAT 4. FAIRLY WELL 5. EXTREMELY WELL

Be sure and record an answer for EVERY statement.

NOTE: Anytime the words parent, mother, father, brother or sister are used, they also mean step-parent, step-mother, etc.

	THIS DESCRIBES MY COPING:	NOT AT ALL	SLIGHTLY	SOMEWHAT	FAIRLY WELL	EXTREMELY WELL
1	Talking to a friend about how I feel	1	2	3	4	5
2	Reading	1	2	3	4	5
3	Going shopping; buying things I like	1	2	3	4	5
4	Listening to music--stereo, radio, etc.	1	2	3	4	5
5	Blaming others for what's going wrong	1	2	3	4	5
6	Talking to a teacher or counselor about what bothers me	1	2	3	4	5
7	Going to my room at home to be alone	1	2	3	4	5
8	Doing a strenuous physical activity (jogging, biking, swimming, etc.)	1	2	3	4	5
9	Eating food	1	2	3	4	5
10	Talking to my father about what bothers me	1	2	3	4	5

	THIS DESCRIBES MY COPING:	NOT AT ALL	SLIGHTLY	SOMEWHAT	FAIRLY WELL	EXTREMELY WELL
11	Getting more involved in activities at school	1	2	3	4	5
12	Riding around in the car	1	2	3	4	5
13	Using drugs (not prescribed by doctor)	1	2	3	4	5
14	Talking to my mother about what bothers me	1	2	3	4	5
15	Smoking	1	2	3	4	5
16	Doing things with my family	1	2	3	4	5
17	Praying	1	2	3	4	5
18	Trying to think of the good things in my life	1	2	3	4	5
19	Going to a movie	1	2	3	4	5
20	Talking to a brother or sister about how I feel	1	2	3	4	5
21	Drinking beer, wine, liquor	1	2	3	4	5
22	Sleeping	1	2	3	4	5
23	Working on a hobby I have (sewing, model building, collections, etc.)	1	2	3	4	5
24	Getting a job or working harder at one	1	2	3	4	5
25	Playing a musical instrument (guitar, piano, drums, etc.)	1	2	3	4	5
26	Going out with friends	1	2	3	4	5
27	Avoiding people and situations that cause me problems or create tension	1	2	3	4	5
28	Telling myself the problem(s) is not important	1	2	3	4	5
29	Writing poetry or stories	1	2	3	4	5
30	Drawing or painting	1	2	3	4	5
31	Writing in a journal or diary	1	2	3	4	5
32	Trying, on my own, to figure out how to deal with my problems or tension	1	2	3	4	5
33	Getting angry and yelling at people	1	2	3	4	5
34	Trying to be funny and making light of it all	1	2	3	4	5
35	Being with my boyfriend or girlfriend	1	2	3	4	5
36	Watching T.V.	1	2	3	4	5
37	Playing pool, pinball, etc.	1	2	3	4	5
38	Trying to ignore it	1	2	3	4	5
39	Trying to stay away from home as much as possible	1	2	3	4	5
40	Working hard on schoolwork or school projects	1	2	3	4	5
41	Learning to live with it	1	2	3	4	5
42	Letting off steam or complaining to my friends	1	2	3	4	5

	THIS DESCRIBES MY COPING:	NOT AT ALL	SLIGHTLY	SOMEWHAT	FAIRLY WELL	EXTREMELY WELL
43	Trying to make new friends	1	2	3	4	5
44	Trying to keep up friendships	1	2	3	4	5
45	Becoming quiet	1	2	3	4	5
46	Trying to make my own decisions	1	2	3	4	5
47	Swearing	1	2	3	4	5
48	Trying to reason with parents and talk things out; compromise	1	2	3	4	5
49	Going along with parents' requests and rules	1	2	3	4	5
50	Crying	1	2	3	4	5
51	Ignoring parents' comments	1	2	3	4	5
52	Misleading people or lying about what I have been doing	1	2	3	4	5
53	Going to church	1	2	3	4	5
54	Trying to get along better with parents	1	2	3	4	5
55	Trying to get along better with brothers/sisters	1	2	3	4	5
56	Trying to keep busy to keep my mind off my problems	1	2	3	4	5
57	Trying to improve myself (e.g., get body in shape, get better grades)	1	2	3	4	5
58	Being careful not to get out of line with parents	1	2	3	4	5
59	Joking and keeping a sense of humor	1	2	3	4	5
60	Saying mean things to people--being sarcastic	1	2	3	4	5
61	Trying to stay out of other people's problems	1	2	3	4	5
62	Trying to help other people solve their problems	1	2	3	4	5
63	Spending time with younger kids	1	2	3	4	5
64	Joing a support group (e.g., Alateen, diet group, study group, etc.)	1	2	3	4	5
65	Organizing my life and what I have to do	1	2	3	4	5
66	Staying home more	1	2	3	4	5
67	Trying not to let things pile up	1	2	3	4	5
68	Being by myself more	1	2	3	4	5
69	Accepting school rules and requirements	1	2	3	4	5
70	Skipping class(es)	1	2	3	4	5
71	Staying out of arguments at home	1	2	3	4	5
72	Playing around with a family pet	1	2	3	4	5
73	Apologizing to people I have hurt	1	2	3	4	5
74	Keeping my feelings to myself	1	2	3	4	5

	THIS DESCRIBES MY COPING:	NOT AT ALL	SLIGHTLY	SOMEWHAT	FAIRLY WELL	EXTREMELY WELL
75	Dropping out of some activities that I'm in	1	2	3	4	5
76	Daydreaming about how I'd like things to be	1	2	3	4	5
77	Getting back at person(s) who cause my problems (revenge)	1	2	3	4	5
78	Trying to see the good things in a difficult situation	1	2	3	4	5
79	Letting off steam or complaining to family members	1	2	3	4	5
80	Getting professional counseling	1	2	3	4	5
81	Talking to a minister/priest/rabbi	1	2	3	4	5
82	Getting more involved in church activities	1	2	3	4	5
83	Doing relaxation exercises (meditation, yoga, etc.)	1	2	3	4	5
84	Engaging in physical contact or rough-housing with someone	1	2	3	4	5
85	Being intimate with someone I care about	1	2	3	4	5
86	Using less alcohol or drugs	1	2	3	4	5
87	Ignoring people who confront me about my behavior	1	2	3	4	5
88	Getting angry and hitting someone	1	2	3	4	5
89	Damaging or stealing property	1	2	3	4	5
90	Driving a car recklessly	1	2	3	4	5
91	Saying nice things ("warm fuzzies") to others	1	2	3	4	5
92	Moping	1	2	3	4	5
93	Doing a relaxing activity (e.g. fishing, walking, etc.)	1	2	3	4	5
94	Using drugs prescribed by a doctor	1	2	3	4	5
95	Getting rid of the problem	1	2	3	4	5

Appendix F

CHRONICITY IMPACT AND COPING INSTRUMENT: PARENT QUESTIONNAIRE

CICI:PQ

THIS QUESTIONNAIRE IS TO HELP US LEARN MORE ABOUT THE EXPERIENCES YOU HAVE IN CARING FOR YOUR CHILD AND THE THINGS YOU DO TO MANAGE THESE EXPERIENCES.

THE INFORMATION YOU SHARE WILL BE USED TO HELP US PROVIDE APPROPRIATE HEALTH CARE TO YOU AND YOUR FAMILY.

PLEASE FEEL FREE TO ASK THE NURSE ABOUT ANY QUESTIONS THAT ARE NOT CLEAR.

TODAY'S DATE _____

CHILD'S NAME: _____ (Family Code)

CHILD'S AGE: _____ / _____
(YEARS) (MONTHS)

CHILD'S SEX: (1) MALE _____ (2) FEMALE _____

SECTION A: YOUR CHILD

1. What is your child's condition or disability?

   _____

2. How severe would you say your child's condition is?

   ___(1)Not severe (slight) ___(2) Moderately severe ___(3) Very severe

3. How long ago was your child's condition first diagnosed?

   ___ (1) under 3 months ___ (4) 1 to 2 years

   ___ (2) 3 to 6 months ___ (5) 2 years 1 month to 4 years

   ___ (3) 7 to 11 months ___ (6) over 4 years

4. Does anyone else in your family have the same illness/disability as your child?

   ___ (1) No ___ (2) Yes

   If yes, who?

   ___ (1) You (CCQ) ___ (4) Grandparent

   ___ (2) Spouse ___ (5) Other: Who?_____

   ___ (3) Child's brother(s) or sister(s)

(OVER)

5. Please indicate your relationship to this child.

___ 1) Mother
___ 2) Father
___ 3) Stepmother
___ 4) Stepfather
___ 5) Foster Mother
___ 6) Foster Father
___ 7) Guardian
___ 8) Other: Explain_____

6. Parents have asked for help with many aspects of their child's development and care including those listed below. Please indicate if you would or would not like to have help with or discuss any of the following:

	Would Not Like (1)	Not Sure (2)	Would Like (3)
Physical care of child			
Diet/nutrition			
Sleep habits			
Genetic counseling			
Play or recreation activities			
Managing child's behavior			
Providing the right play and learning experiences			
Care of minor illnesses			
Dental needs of child			
Information about expected child development			
Information about my child's physical development			
Information about my child's social development			
Information about my child's emotional development			
Information about my child's intellectual development			
Information about my child's condition			
Other: What?			

7. What have you done in the past when you have needed information or help with any of the areas listed in Question 6 ? (Please check as many as apply.)

___ 1) Have not need help (031)
___ 2) Wrote away to others
___ 3) Asked the clergy
___ 4) Went to the library
___ 5) Asked nurse or doctor
___ 6) Asked friends or relatives
___ 7) Asked other parents
___ 8) Nothing
___ 9) Talked to others
Who?_____
___10) Have not known what to
___11) Other: What?_____

SECTION B: YOURSELF

1. All parents have some areas of concern. During the past 3 months, how much of a concern have the following areas been for you? (Please put an "X" in the appropriate column.)

CONCERNS	None/Does not apply (1)	Not Sure (2)	A little bit (3)	Quite a bit (4)	A great deal (5)
Extra demands on my time					
Feeling worn out					
Enough fun and relaxation as I would like					
Having enough time alone with spouse/partner					
Talking with or understanding my spouse/partner					
Sexual relationship with my spouse/partner					
Making my child comfortable or happy					
Enough time or attention from spouse/partner					
Getting out of house together with spouse/partner but without children					
Getting out of house alone					

(OVER)

Concerns (cont'd)	None/Does not apply (1)	Not Sure (2)	A little bit (3)	Quite a bit (4)	A great deal (5)
Getting to do activities together as a family					
Whether I am taking care of my child in the best way					
Having to travel too far for medical help or child care					
The weather influencing what my child is able to do					
Having enough insurance to meet expenses of child care					
Having adequate agencies in the community providing care related to my child's needs					
Wondering about what my child's future is likely to be					
The responsibility of caring for my child worries me					

2. Parents handle their concerns in many different ways. There are times when you may have more problems and concerns because of your child's condition. In what ways do you do things differently when these problems come up? (Plese put an "X" in the appropriate column. DO NOT mark on the lines.)

	Does Not Apply (1)	Do Less (2)	Do About the Same (3)	Do More (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke more				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take more alcohol				
Pray				
Take more medicine				

3. Are you a member of a parent's association related to your child's illness disability?

___ (1) No ___ (2) Yes

a. If Yes, how often do you attend meetings?

___ (1) Frequently ___ (3) Rarely

___ (2) Occasionally ___ (4) Never

b. If you go to the parents meetings, how helpful have they been?

___ (1) Do not go ___ (4) Not very helpful

___ (2) Very helpful ___ (5) Not helpful at all

___ (3) Somewhat helpful

4. Do you have someone who could take care of your child for a day in case of an emergency (such as you become ill and cannot take care of the child)?

___ (1) No ___ (2) Not sure ___ (3) Yes

5. Do you have someone who could take care of your child for a week or more in case of an emergency?

___ (1) No ___ (2) Not sure ___ (3) Yes

6. Parents have different beliefs about many things that influence their life style. Please indicate whether or not you agree with the beliefs stated below.

Beliefs	Agree (1)	Not Sure (2)	Disagree (3)
Parents should take care of their own needs before they can help their children			
It is necessary to get out of the house often to relieve the strain of child care			
It is usually better not to show or talk about one's feelings to others			
Sometimes just avoiding or trying to forget something makes it easier to handle			
Sometimes just getting away from a situation makes it easier to handle			
I usually have control over things that happen to me or my family			
It is lucky that this is the only condition my child has			
My child's condition is always going to be there and there isn't much I can do about it			
I sometimes think of my child's condition as a nuisance			

7. a) What is your marital status?

___ (1) Married ___ (4) Divorced

___ (2) Widowed ___ (5) Single (never married)

___ (3) Separated

b) For how many years have you been widowed, married, separated, or divorce

___ (1) under 1 year ___ (3) 4-6 years

___ (2) 1 - 3 years ___ (4) over 6 years

(OVER)

c) How many times have you been married?

___ 1
___ 2
___ 3 or more

IF YOU ARE MARRIED, PLEASE GO ON TO SECTION C
IF YOU ARE NOT MARRIED, PLEASE GO ON TO SECTION D

SECTION C. YOUR SPOUSE

IF YOU ARE WIDOWED, DIVORCED, SEPARATED, OR SINGLE, PLEASE GO ON TO SECTION D.

1. How old is your spouse?

___ (1) under 18 years
___ (2) 19 - 24 years
___ (3) 25 - 29 years
___ (4) 30 - 34 years
___ (5) 35 - 39 years
___ (6) 40 - 44 years
___ (7) 45 - 49 years
___ (8) 50 years or over

2. What is your spouse's occupation? (Please state what your spouse does, not where he/she is employed.)

_____

3. How much school has your spouse completed?

___ (1) 9th grade or below
___ (2) 10th grade
___ (3) 11th grade
___ (4) 12th grade
___ (5) Some college
___ (6) College graduate
___ (7) Master's degree
___ (8) Doctoral degree

4. How has your spouse's health been during the past 3 months?

___ (1) Excellent
___ (2) Very good
___ (3) Good
___ (4) Fair/poor

5. During the past 3 months how much of a problem do you think have the following areas been for your spouse? (Place an "X" in the appropriate column. Please do not mark on the lines.)

Problems for Spouse	Does Not Apply (1)	Not Sure (2)	A Little Bit (3)	A Moderate Amount (4)	A Great Deal (5)
Extra demands on time					
Feeling worn out because of all the family's needs					
Not enough fun and relaxation as spouse would like					
Not enough time or attention from you					
Having enough time alone with you					

Problems for spouse (cont'd)	Does Not Apply (1)	Not Sure (2)	A Little Bit (3)	A Moderate Amount (4)	A Great Deal (5)
Talking with or understanding you					
Sexual relationships with you					
Making your child comfortable or happy					
Getting out of house together with you but without children					
Getting out of house alone					
Getting to do activities together as a family					
Whether you are taking care of your child in the best way					
Having to travel too far for medical help or child care					

6. How satisfied are you with your relationship with your spouse?

___ (1) Not sure
___ (2) Very satisfied
___ (3) Somewhat satisfied
___ (4) Somewhat dissatisfied
___ (5) Very dissatisfied

7. People do many different things when they become upset with their spouse. Please indicate the ways in which you do things differently when you are upset with your spouse than when your are not upset. (Please put an "X" in the appropriate box. Do not mark on the lines.

	Does Not Apply (1)	Do Less (2)	Do About The Same (3)	Do More (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke more				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take more alcohol				
Pray				
Take more medicine				

(OVER)

8. In what ways does your spouse do things differently when upset with you than when not upset? (Please put an "X" in the appropriate box. Do Not mark on the lines.)

	Does Not Apply (1)	Do Less (2)	Do About The Same (3)	Do More (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke more				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take more alcohol				
Pray				
Take more medicine				

9. How has your relationship with your spouse changed since your child's condition was diagnosed?

___ (1) No change ___ (3) Brought us closer

___ (2) Not sure ___ (4) Moved us apart

IF YOUR CHILD HAS SISTERS OR BROTHERS, PLEASE GO TO SECTION D

IF YOU CHILD DOES NOT HAVE SISTERS OR BROTHERS, PLEASE GO TO SECTION E

SECTION D. BROTHERS & SISTERS

1. During the past 3 months, how much have you and your other children talked about the following:

	Not at all/Does not apply (1)	A Little Bit (2)	A Moderate Amount (3)	A Great Deal (4)
Information about the child's condition				
How to take care of the condition				
Their friends				
School				
Activities				

1. Continued	Not at all/Does not apply (1)	A Little Bit (2)	A Moderate Amount (3)	A Great Deal (4)
Child's behavior in general				
Their future				
Growing up in general				

2. Please indicate whether you would like to have help with or discuss any of the following in relation to any of your child's brothers or sisters/

	Would Not Like (1)	Not Sure (2)	Would Like (3)
Information about expected child development			
Managing child's behavior			
Physical needs			
Emotional needs			
Social needs			
Intellectual needs			
Helping child understand the othe child's condition			
Helping children to get along			

SECTION E. HOSPITALIZATION

1. Has your child ever been admitted to the hospital?

___ (1) No - (If No, please complete Section F.)

___ (2) Yes - (If Yes, please complete this section)

2. How many times has your child been in the hospital?

___ (1) 1 ___ (3) 5 - 7

___ (2) 2 - 4 ___ (4) 8 or more

3. For how long were the majority of hospital stays?

___ (1) under 1 week

___ (2) 1 - 2 weeks

___ (3) over 2 weeks

4. At what ages was your child admitted to the hospital? (Check as many as

___ (1) under 1 year ___ (5) 10 - 12 years

___ (2) 1 - 2 years ___ (6) 13 - 15 years

___ (3) 3 - 5 years ___ (7) 16 - 18 years

___ (4) 6 - 9 years ___ (8) over 18 years

5. How satisfied were you with the care your child received during the last hospitalization?

___ (1) very satisfied ___ (3) somewhat dissatisfied

___ (2) somewhat satisfied ___ (4) very dissatisfied

SECTION F. OTHER

1. How many children do you have?

___ 1 ___ 3 ___ 5 ___ 7

___ 2 ___ 4 ___ 4 ___ 8 or more

2. How many of your children are under 5 years of age?

___ 0 ___ 1 ___ 2 ___ 3 ___ 4 or more

3. How many of your children are between 6 and 12 years of age?

___ 0 ___ 1 ___ 2 ___ 3 ___ 4 or more

4. How many of your children are 13 years old or older?

___ 0 ___ 1 ___ 2 ___ 3 ___ 4 or more

5. In general, how has the health of each of your children been during the past 3 months?

	Excellent/ Very good (1)	Good (2)	Fair/ Poor (3)
Child 1 (with disease/disability			
Child 2			
Child 3			
Child 4			
Child 5			
Child 6			
Child 7			
Child 8			

6. How would you describe yourself?

___ 1) Caucasian ___ 3) Black ___ 5) Native American

___ 2) Asian ___ 4) Spanish-American ___ 6) Other(Please specify_____

7. What is your religion?

___ 1) Catholic ___ 3) Protestant ___ 5) No religion

___ 2) Jewish ___ 4) Other. What?_____

8. How often have you attended religious services in the past 3 months?

___ 1) Frequently ___ 2) Occasionally ___ 3) Rarely ___ 4) Never

9. Are you employed now?

___ 1) No ___ 2) Yes

a. If yes, what do you do? _____
(Please do not put where you work)

b. If yes, do you work? ___ 1) full time? ___ 2) part-time

10. Are you satisfied with your current employment status?

___ 1) No ___ 2) Not sure ___ 3) Yes

11. What is your age?

___(1) under 18 years ___ (4) 30 - 34 years ___ (7) 45 -49 years

___(2) 19 - 24 years ___ (5) 35 - 39 years ___ (8) 50 years or over

___(3) 25 - 29 years ___ (6) 40 - 44 years

12. How much school have you completed?

___(1) 9th grade ___ (4) 12th grade ___ (7) Master's degree

___(2) 10th grade ___ (5) Some college ___ (8) Doctoral degree

___(3) 11th grade ___ (6) College graduate

13. How has your general health been during the past 3 months?

___(1) Excellent ___(2) Very Good ___ (3) Good ___ (4) Fair/Poor

14. What is your family's annual income?

___ 1) Under $5,000 ___ 3) $11,000 to $20,000 ___ 5) Over $30,

___ 2) $5,000 to $10,000 ___ 4) $21,000 to $30,000

15. Approximately how many of the questions in this questionnaire apply to your child and family?

___ (1) All ___ (2) Most ___ (3) Some ___ (4) Few ___ (5) None

16. How well do the questions cover the things you believe are important about having your child with this condition?

___ (1) Very well ___ (3) Not too well

___ (2) Somewhat well ___ (4) Not very well at all

17. How long did it take you to complete this questionnaire?

___ (1) under 10 minutes ___ (3) 15 - 19 minutes ___ (5) 25 minutes or more

___ (2) 10 - 14 minutes ___ (4) 20 - 24 minutes

18. Do you have anything else to add that you would like us to know about your self, your child or other family members?

___ (1) No

___ (2) Yes

If yes, what? _____

Appendix G

Code No. A

IDENTIFIED STRESSORS OF ADOLESCENTS WITH CYSTIC FIBROSIS: ADOLESCENT QUESTIONNAIRE

Q. 1 Please rate on a scale from 1 to 10 how helpful the following persons or resources are to you with your illness. 1 is not at all helpful, 5 is moderately helpful, and 10 is extremely helpful.

	1	2	3	4	5	6	7	8	9	10
My doctors										
My nurse										
My social worker										
My dietician										
Other members of my health team (please state below)										
My brothers and sisters										
My relatives										
My friends with cystic fibrosis										
My friends										
Members of my church										
My pastor										
Community agencies (please state below)										
Cystic Fibrosis Foundation										
Books (please state below)										
My teacher										

Q. 2 Please rate on a scale of 1 to 10 how bothersome your illness is to you. 1 is not at all bothersome, 5 is moderately bothersome, and 10 is extremely bothersome.

1	2	3	4	5	6	7	8	9	10

Q. 3 Please rate on a scale of 1 to 10 how bothersome the following conditions of your illness are to you. 1 is not at all bothersome, 5 is moderately bothersome, and 10 is extremely bothersome.

	1	2	3	4	5	6	7	8	9	10
Cost of the illness										
Time and energy required for treatment regime										
Frequency of visits to the doctor or hospital										
Interference with normal family activities										
Restricts family vacations to nearby area										
Diet										
Odorous stools										
Frequent chest physiotherapy										
Numerous medications										
Other (describe)										

Q. 4 Please rate on a scale of 1 to 10 how consistently you follow your treatment regime (i.e., doctor's orders, diet, medications, chest physiotherapy). 1 is never, 5 is most of the time, and 10 is always.

1	2	3	4	5	6	7	8	9	10

Q. 5 Have your religious beliefs changed since your diagnosis? Yes____ No____
If yes, how?

On a scale of 1 to 10 please rate how religious you are. 1 is not religious, 5 is moderately religious, and 10 is religious all the time.

1	2	3	4	5	6	7	8	9	10

Q. 6 On a scale of 1 to 10 please rate how involved your son/daughter is in regard to decisions concerning his/her medical care. 1 is not involved, 5 is moderately involved, 10 is involved all the time.

1	2	3	4	5	6	7	8	9	10

Q. 7 Do you encourage school attendance and participation for your son/daughter?
Yes_____ No_____ If not, why?

Q. 8 Has the school reported academic or social difficulties with your son/daughter?
Yes_____ No_____ If yes, what difficulties have occurred?

Q. 9 Do you communicate with the school to facilitate adjustment of your son/daughter's illness? Yes_____ No_____ If yes, what have you communicated?

Q. 10 Do you feel your son/daughter's teachers understand his/her illness?
Yes_____ No_____

Q. 11 On a scale of 1 to 10 please rate how much your spouse participates with your son/daughter's medical care. 1 is not involved, 5 is moderately involved, 10 is involved all the time.

1	2	3	4	5	6	7	8	9	10

Q. 12 With regard to your son/daughter's illness, which areas would you like your spouse to be more actively involved?

Q. 13 **Is there any other information or issues you would like to discuss which would help health professionals learn more about your concerns?**

Thank you for your assistance.

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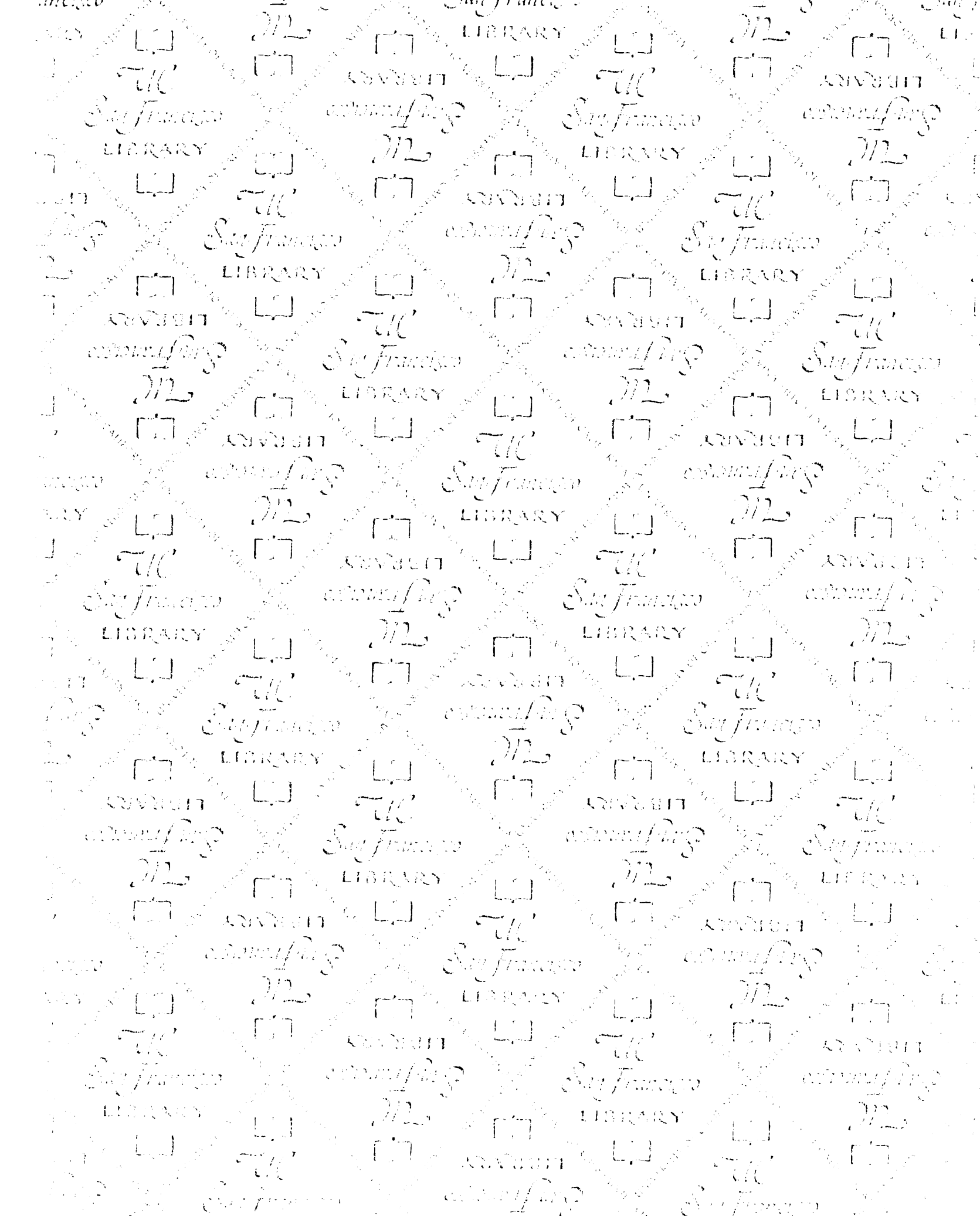
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