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Predictors of health maintenance behavior of young adults with cystic fibrosis

Kimchi, Judith, Ph.D.

The Ohio State University, 1992
PREDICTORS OF HEALTH MAINTENANCE BEHAVIOR
OF YOUNG ADULTS WITH CYSTIC FIBROSIS

DISSERTATION

Presented in Partial Fulfillment of the Requirements
for the Degree Doctor of Philosophy
in the Graduate School of
The Ohio State University

By
Judith Kimchi, B.S.N., M.S.

* * * *
The Ohio State University
1992

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Dedication

To my children Ethan and Sharon Kimchi
may all your dreams come true
ACKNOWLEDGEMENT

My sincere thanks to my mentor Dr. Joanne S. Stevenson for her guidance and support throughout this research project, and for always "keeping me on my toes" and teaching me how to expand my gray cells to reach beyond. My sincere thanks also to Dr. Michelle Walsh and Dr. Patrick McKenry for their personal interest in my academic endeavors and their warm encouragement and support at trying times. Special appreciation is extended to Dr. Karen McCoy for her professional advise, suggestions, and comments. The assistance of John Hayes in the statistical analysis, Wanda Newman in data entry and typing, and Marita Eichensehr in pulmonary function calculations, is gratefully acknowledged. Special recognition is given to my friends Barbara Polivka and James Woods III for their emotional support, patience, and helpful words of encouragement. Special thanks are extended to Judy and Yossi Nygate for their help throughout this academic endeavor. My thanks to all the CF clinic directors for encouraging their patients to participate in the study, and all the health professionals who helped in the data collection phase. Finally, to my husband Menachem, and my children Ethan and Sharon, I offer my love and sincere gratitude for believing in me and helping me every step of the way. At last - "Mommy-Doctor-Nurse" - is a reality.
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CHAPTER I

Introduction

Cystic fibrosis (CF) is the most common lethal genetic disease in Caucasians. Prior to 1945 the prognosis was very poor and the majority of patients died in infancy. In the 1950s, the median survival age was three years, whereas in 1966, the average survival age was 11 years. With medical and technological advances, improvement in care ensued. During the last decade, CF patients survived into their 20s, and in some cases, well beyond their 30s (Murphy, 1987). Since young adults constitute a fairly new population, only a small number of studies on psychosocial aspects related to their CF condition have been conducted to date. None of these studies have looked at their health maintenance behaviors, the origin of these behaviors, or the outcome of these behaviors as they relate to their physical condition. Knowledge about health behaviors of young adults with cystic fibrosis is limited.

Cystic fibrosis is a chronic condition and as such necessitates very involved and time consuming daily care.
The daily treatment program includes secretion removal by postural drainage 2-3 times a day, breathing and physical exercises, aerosol therapy, vitamin and pancreatic enzymes, and nutritional supplementation. Most health maintenance behaviors of children with CF are carried out and controlled by their families. Studies of health maintenance behaviors of families with children and adolescents with CF have been extensively reported in the literature. However, health maintenance behaviors of young adults with CF have not been studied.

There are several determinants of one's health behaviors: health locus of control is hypothesized to be one important factor. Individuals' health behaviors may be affected by their locus of control (LOC). The basic premise of this construct is that individuals who expect outcomes to be the result of their own behaviors are categorized as internal in their LOC, whereas individuals who expect outcomes to relate to either powerful other people or to be randomly determined by chance, or fate, are categorized as having an external locus of control (Rotter, 1966). Results of research conducted with the various LOC instruments suggest that beliefs about internal versus external control are related in significant ways to health-related behaviors and overall sense of health (Burgess et al., 1988; Frank & Elliott, 1989; Galgut et al., 1987; Huckstadt, 1987; Kerr,
1986; Kirsch, 1972; Weerdt et al., 1990). With some exceptions, the bulk of the reported research on internal LOC and external LOC and health practices lends credence to the expected theoretical assumption that individuals who hold internal as opposed to external expectancies are more likely to assume responsibility for their own health.

The family of origin may be a crucial factor in the development of one's locus of control. Families affect members' views of their ability to care for themselves in light of a specific condition. Some families may foster independence, others may encourage dependence. It seems that warmth, supportiveness and parental encouragement are essential to the development of internal locus of control whereas parental control, inconsistent discipline and withdrawal seem to foster the development of external LOC (Lefcourt, 1982).

Cystic fibrosis in young adulthood has recurrent symptoms and is progressively disabling as body organs deteriorate with age. Many physical as well as psychological challenges face young adults with CF on a daily basis. At a period when they are trying to accomplish tasks of young adulthood, they also have to devote time for their own physical care. Understanding some of the variables that help young adults manage their life and physical condition successfully, may provide health professionals with knowledge
that may be applied to families of young children with CF. The purpose of this study was to assess and test possible predicting variables that affect health maintenance behaviors of young adults with cystic fibrosis.

Research Questions

1. What is the health maintenance behavior profile of young adults with cystic fibrosis?
2. What is the family-type profile of young adults with cystic fibrosis and healthy young adults and is there a difference between them?
3. Is there a difference between health locus of control characteristics of young adults with cystic fibrosis and healthy young adults?
4. Do family type, health locus of control, demographic variables, or severity of illness correlate with health maintenance behaviors of young adults with cystic fibrosis?
5. Do family type and health locus of control variables predict health maintenance behaviors of young adults with cystic fibrosis?
Operational Definitions

1. Healthy adults - persons free of acute or chronic illness or major injury at time of participation.

2. Person with CF - a person that has been diagnosed by a physician as having cystic fibrosis. The diagnosis of CF is usually established by repeated findings of elevated sweat chloride levels (more than 60 meq/liter) by the quantitative pilocarpine iontophoresis method (Huang et al., 1987). Pulmonary involvement assessed by clinical symptoms, chest roentgenographic appearance, sputum bacteriologic results, and pulmonary function measurements. Pancreatic function usually is determined by duodenal enzyme assay or indirectly by the measurement of fecal fat.

3. Health maintenance behaviors - activities which are performed on a routine basis (daily, weekly, or periodically) in order to maintain one's present level of health.

4. Control - refers to the person's expectancy that outcome is contingent on his/her actions. The greater the expected contingency between acts and outcomes, the more control the person perceives he has.

5. Locus of control (LOC) - the degree to which individuals perceive the events that happen to them as dependent on
their own behavior (internal), or as a result of luck, chance, fate, or powerful others, beyond one’s personal control and understanding (external).

6. Health locus of control (HLOC) - the degree of which a person perceives control over his own health as measured by the Multidimensional Health Locus of Control.

7. Family type - one of each of the 16 family types as measured by FACES III, which range from extreme family types that have too little or too much cohesion and adaptability to balanced family types with moderate levels of cohesion and adaptability.

Significance

In recent years, the Division of Lung Diseases, National Heart, Lung, and Blood Institute (NHLBI) in cooperation with the National Institute of Diabetes and the Cystic Fibrosis Foundation formally recognized that inadequate attention has been given to self-management behaviors of young adults with cystic fibrosis (Eigen et al., 1987). Studies that examine psychological factors that may alter the pathophysiology in CF patients by influencing compliance with treatment were then encouraged. Although compliance is not the focus of this proposed study, health maintenance behaviors that are
carried out on a regular basis in order to maintain one’s present health status (not merely complying with prescribed treatment) are certainly related.

One of the factors which may affect one’s decision to engage in health maintenance behaviors is health locus of control (Wallson & Wallson, 1982). Understanding the variables that affect the development of health locus of control (HLOC) of young adults with CF, may have implications for patient care.

Arakelian (1980) stated that locus of control is a relatively stable personality factor developed over time and acquired through a series of many social learning experiences. However, changes in expectancies can be brought about by introducing new experiences that alter previous success and failure patterns. Viewed in this light, the potential exists for changing a person’s locus orientation. Since internal locus of control may influence the overall health of the person with CF with potential contribution to longevity, it merits attention. Locus of control is not a conclusive predictor of health behaviors, but it can lend valuable insight into the decisions regarding the most efficacious nursing approach with clients displaying various health behaviors and beliefs.

Assessment of the health locus of control orientation of young adults with CF may be incorporated into client care.
The purpose of incorporating it into client care is not to label clients as internal or external, but rather to gain insight into their orientation on the internal-external continuum. Health care providers may be able to take advantage of opportunities to understand adults as they are, how they might change, and how learning may be facilitated to enable them to take responsibility for their own health and health care. These assessment data will guide care providers in their approach to client's care. The optimal approach may be that of self-care for internally oriented clients while externally oriented clients may benefit from a more directive approach (Shillinger, 1983). Using this construct, the plans of care for these patients could more effectively correspond to health locus orientation of clients.

Findings for adults may later be extrapolated to be used in the care of families with children and adolescents. Programs may be developed to guide families and children through behaviors that foster the development of internal health locus of control characteristics that may help them maintain their health as young adults.
CHAPTER II

Theoretical Framework

The theoretical framework for this research is based on three models - The Health Belief Model (HBM), Systems Model, and the Circumplex model; and two theoretical constructs - individuation and health locus of control (HLOC).

The Health Belief Model will be used to explain the perceptions of health of young adults with cystic fibrosis (CF), the modifying factors in their decision to carry out health maintenance behaviors, and the likelihood that such actions will occur. The systems model, as it relates to families, serves as a basis for both the HBM and the Circumplex model. Families are viewed as a whole, open system with interdependent parts where individuals affect each other through interaction. The circumplex model measures families on dimensions of cohesion and adaptability and will be used to map out types of family-of-origin. The two theoretical constructs—individuation and health locus of control— are interrelated. The type of HLOC one has as an adult is thought to be the product of its acquisition during the individuation process in the adolescent years. In the same vein, the health maintenance behaviors practiced in adulthood are thought to be related to the type of HLOC one
has. Internal health locus of control is considered to be the best control a chronically ill person could have since one’s sense of control over his own health is believed to be the most conducive for engaging in health maintenance behaviors. In CF as in other chronic illnesses the process of individuation may be altered and because of it, so is the acquisition of HLOC. Thus, chronically ill adolescents may reach adulthood ill-equipped to carry out health maintenance behaviors that might help them sustain their health for many years.

Cystic fibrosis (CF) is a chronic illness. Chronic illness is defined as all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathologic alteration, may require long periods of supervision, observation and care (Mayo, 1956). Although Mayo’s definition dates back to 1956, it is still widely used. Indeed, CF is continually symptomatic and it progresses in severity. Since there is no cure, treatment is essentially supportive and individualized (CF Foundation, 1981).

The primary setting for treating CF is the home. The family is viewed as a whole, open system with interdependent parts where individuals affect each other through interaction. The family system processes input and output of
information, it has internal control and a feedback process that maintains a steady state. The feedback and control mechanisms enable the system to be adaptable (Duldt & Giffin, 1985). Successful management of the child with CF depends on the ability of his family to adapt, to alter its lifestyle to accommodate the time-consuming demands of a complex treatment regimen and to follow the recommendations of the health care team. Family members must spend several hours each day preparing special diets, administering medications, performing postural drainage and aerosol therapies, and cleaning equipment. The child depends on parents for care and depends on pediatrician and clinic staff for disease management.

Families have profound effects on the growth and development of children and adolescents into young adults. The family system influences individuals’ view of themselves. As children with CF grow up and reach adolescence, part of their adult identity and their self perception will be determined by the ongoing interaction with their family throughout their adolescent years.

Adolescence is the process of becoming an adult, it is the time for the emergence of “the self”. One of the processes that an adolescent must go through is the process of individuation. According to Karpel (1976), individuation is the process by which a person becomes increasingly
differentiated from a past or present relational context. This process, encompasses a multitude of intrapsychic and interpersonal changes that share a common direction: "Individuation involves subtle but crucial phenomenological shifts by which a person comes to see him/herself as separate and distinct within the relational context in which s/he is embedded" (Hill & Palmquist, 1978). Both identity formation and mature role-taking ability require the adolescent to possess a viewpoint, to be aware of other views, and both to integrate and to differentiate his or her own views from those of others. In identity formation, these skills can be seen in the identification and active exploration of alternatives for the future and in the integration of these possibilities into a coherent, consistent sense of self. In role taking, these skills can be seen in the identification of other social perspectives and in the coordination of these perspectives into an interpersonally viable mode of relating to others. Wide individual differences exist in adolescents capacity to employ these skills, because their application is greatly influenced by contextual factors and because individual differences exist in the cognitive skills on which they are based (Hill & Palmquist, 1978). This developmental process involves learning how to make decisions and how to deal with success and failure. It includes making relatively simple decisions about what time
to go to bed, which aerosol to use, or whom to date. Success in these concrete decision-making milestones allows one to venture into more complex decision-making tasks such as marriage, career, independent living arrangements, and caring for self.

Achieving individuation may be difficult when one has a chronic illness. Chronic, ongoing illness exerts a powerful pull toward relinquishing control and decision-making responsibilities to others. This is precisely opposite to the force that pushes adolescents toward taking control over their own lives and becoming adults (Coupey & Cohen, 1984). Experimentation and errors are the hallmarks of this independence struggle, and these, of course, are at variance with the treatment of chronic disease, where errors in judgment can be life-threatening and experimentation is discouraged (Coupey & Cohen, 1984).

The problem of independence for the chronically ill adolescent centers around the fact that, concerning the illness, it often seems as if he or she has nothing left to decide. This is particularly true if the health care providers and the family are overprotective and do not inform or involve the teenager in the decision making process. It is important to allow adolescents to make decisions about their illness so they can gain a sense of mastery and Control. Perceived control is especially important in adolescence, and
achieving a sense of greater personal autonomy is a fundamental task (Spirito et al., 1984). It is only through a gradual acceptance of responsibility for self-care that the young teenager will, over a few short years, eventually acquire the skills necessary to function as a competent adult with a chronic illness (Coupey & Cohen, 1984).

Another difficulty that faces chronically ill adolescents is that they may never be allowed or encouraged to even begin to struggle for self-sufficiency. Teenagers who are particularly at risk for this difficulty are those who have had a severe illness since early childhood such as CF. Those young people who never strive for independence at all can become emotionally, socially, and economically dependent, and become unproductive, unhappy adults.

The issue of achievement of independence and a successful completion of the process of individuation by adolescents and young adults with CF have not been studied much. Only two review articles were found which described the difficulties of adolescents with CF in achieving developmental tasks (Mearns, 1986; Naccarato & Kresevic, 1989). Overprotectiveness by parents of adolescents with CF and problems with achievement of independence were mentioned by some authors (Bywater, 1981; Mitchell-Heggs et al., 1976; Mrazek, 1985; Tavorina et al., 1976; Tropauer et al., 1970). All the accounts were a sentence or two in length, and the
topic was not the focus of any of the cited works. On the other hand, several studies have shown young adults with CF to be independent, living on own, married, and holding variety of jobs or attending college (Cowen et al., 1984; Strauss and Wellisch, 1981).

Although these structural aspects demonstrate accomplishment of several developmental tasks of young adulthood (e.g., marriage, living on own), none indicate the accomplishment of individuation. None of the studies examined: a) spousal relationships, such as overprotectiveness of one spouse over the ill spouse; b) the healthy spouse as a substitute parent assuming major responsibilities for treatments, medications, and clinic appointments; c) and dependency role relationships. These relational aspects in one’s family of procreation seem to be more appropriate indicators of achievement of individuation, than the structural indicators mentioned above. However, in this research only one relational aspect, assumption of responsibilities, will be studied.

Because of the chronic, life threatening nature of CF and the contextual variables discussed thus far, it is conceivable to assume that the individuation process of adolescents may be hindered in many families. Because of the obstacle to individuation and development of independence, young adults with CF may reach adulthood dependent on others
for their care or not caring for themselves appropriately.

The types of family-of-origin of young adults with CF and healthy young adults will be mapped out using the Circumplex model (see Figure 1 & Figure 2). According to the Circumplex Model of Marital and Family Systems (Olson, 1986), which is based on family cohesion, adaptability, and communication, families may be categorized into one of 16 types or three more general types, i.e., balanced, mid-range, and extreme families. It may be used with a variety of family structures including nuclear families, blended families, and single-parent families.

Family cohesion is defined as the emotional bonding that family members have toward one another. Within the Circumplex Model, some of the specific concepts or variables that can be used to measure the family cohesion dimensions are: emotional bonding, boundaries, coalitions, time, space, friends, decision-making, and interests and recreation. There are four levels of cohesion, ranging from disengaged (very low) to separated (low to moderate) to connected (moderate to high) to enmeshed (very high). It is hypothesized that the central levels of cohesion (separated and connected) lead to optimal family functioning. The extremes (disengaged or enmeshed) are generally seen as problematic. When cohesion levels are high (enmeshed system), there is too much consensus within the family and too little independence. A
FIGURE 1. CIRCUMPLEX MODEL: SIXTEEN TYPES OF FAMILY SYSTEMS

FIGURE 2. FAMILY SYSTEM TYPES
From FACES III (p.31) By D. H. Olson Author,1985, St. Paul, MN: Social Sciences, University of Minnesota.
the other extreme (disengaged system), family members “do their own thing”, with limited attachment or commitment to their family. In the model’s central area (separated and connected), individuals are able to experience and balance these two extremes and are able to be both independent from and connected to their families.

A disengaged relationship often has extreme emotional separateness. There is little involvement among family members and there is a lot of personal separateness and independence. People often do their own thing and have separate interests.

A separated relationship has some emotional separateness but it is not as extreme as the disengaged system. While time apart is important, there is some time together and some joint decisions. Activities and interests are generally separate but a few are shared. A connected relationship has some emotional closeness and loyalty to the relationship. Time together is more important than time apart to be by oneself. There is a emphasis on togetherness. While there are separate friends, there are also friends shared by the rest of the family. There are often shared interests.

In the enmeshed relationship, there is an extreme amount of emotional closeness and loyalty is demanded. Persons are very dependent on each other and reactive to one another. There is a general lack of personal separateness and little
private space is permitted. The energy of the persons is mainly focused inside the family and there are few outside individual friends or interests. It is being hypothesized that individuation will be most hindered in this type of family.

Based on the Circumplex model, high levels of cohesion (Enmeshed) and low levels of cohesion (Disengaged) might be problematic. On the other hand, families with moderate scores (Separated and Connected) are able to balance being alone versus together in a more functional way. Although there is no absolute best level for any family, some may have problems if they always function at either extreme of the family map (Disengaged and Enmeshed).

Family adaptability (change) is defined as the ability of a family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress. In order to describe and measure families on this dimension, a variety of concepts have been taken from several social science discipline, with heavy reliance on family sociology. These concepts include: family power (assertiveness, control, discipline) negotiation styles, role relationships and relationship rules.

The four levels of adaptability range from rigid (very low) to structured (low to moderate) to flexible (moderate to high) to chaotic (very high). As with cohesion, it is
hypothesized that central levels of adaptability (structured and flexible) are more conducive to family functioning, with the extremes (rigid and chaotic) being the most problematic for families as they move through the family life cycle.

Basically, adaptability focuses on the ability of the family system to change. Families can range from having a rigid and authoritarian leader to being chaotic with erratic or limited leadership. A rigid relationship occurs when one person is highly controlling. The roles are strictly defined and the rules do not change. It is speculated that individuation will be most hindered in this type of family. A structured relationship is overall less rigid. Leadership is somewhat less authoritarian and controlling, and is shared between the parents. Roles are stable, but there is some sharing of roles. There are a few rule changes, but not a lot of change. A flexible relationship is even less rigid. Leadership is more equally shared. Roles are sometimes shared and rules could change. A chaotic relationship has erratic or limited leadership. Decisions are impulsive and not well thought out. Roles are unclear and often shift from person to person.

Based on the Circumplex Model, very high levels of change (chaotic) and very low levels of change (rigid) might be problematic for a family. On the other hand, families having moderate scores (structured and flexible) are able to
balance some change and some stability in a more functional way. Although there is no absolute best level, many families may have problems if they always function at either extreme of the family Map (rigid and chaotic).

Family communication is the third dimension in the Circumplex Model, and is considered a facilitating dimension. Communication is considered critical for facilitating families to move on the other two dimensions. Because it is a facilitating dimension and not measured, communication is not graphically included in the model.

An important distinction in the Circumplex Model is between balanced and extreme types of family relationships. There are four balanced types that are "separated" or "connected" levels on cohesion and "structured" or "connected" on adaptability. The four extreme types are "disengaged" or "enmeshed" on cohesion and "rigid" or "chaotic" on adaptability. Figure 3 describes in some detail the characteristics of the four balanced relationships and a description of the four extreme relationships: chaotically disengaged, chaotically enmeshed, rigidly disengaged and rigidly enmeshed.

The central hypothesis derived from the model is that balanced families will function more adequately than extreme families. This hypothesis is based on the assumption that family extremes on both dimensions will tend to have more
CHAOTICALLY DISENGAGED

Chaotic on Adaptability
- Erratic leadership, unsuccessful parental control, ineffective discipline, inconsistent consequences, impulsive decisions, endless negotiation, lack of role clarity, role reversals, frequent rule changes.

Dissociated on Cohesion
- Extreme emotional separateness, lack of family loyalty, very little involvement with each other, very little sharing of feelings, lack of parent-child closeness, separateness preferred, independent decision making, little time together, a lack of family loyalty.

CHAOTICALLY ENMESHED

Chaotic on Adaptability
- Erratic leadership, unsuccessful parental control, ineffective discipline, inconsistent consequences, impulsive decisions, endless negotiation, lack of role clarity, role reversals, frequent rule changes.

Enmeshed on Cohesion
- Extreme emotional closeness, loyalty to family demanded, very dependent on one another, little private space permitted, lack of generational boundaries, energy mainly focused inside the family, few individual friends permitted, very reactive emotionally, decisions are subject to the wishes of the whole group.

Balanced Systems

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<th>Flexible</th>
<th>Structured</th>
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Flexible
- Extreme emotional separateness, loyalty to family demanded, very dependent on one another, little private space permitted, lack of generational boundaries, energy mainly focused inside the family, few individual friends permitted, very reactive emotionally, decisions are subject to the wishes of the whole group.

Structured
- Extreme emotional separateness, loyalty to family demanded, very dependent on one another, little private space permitted, lack of generational boundaries, energy mainly focused inside the family, few individual friends permitted, very reactive emotionally, decisions are subject to the wishes of the whole group.

FIGURE 3. CIRCUMPLEX MODEL
(Balanced and Extreme Types)
difficulties functioning across the life cycle. This assumes a curvilinear relationship on the dimensions of cohesion and adaptability. This means that too little or too much cohesion or adaptability is seen as dysfunctional to the family system. However, families that are able to balance between these two extremes seem to function more adequately. In studies of normal families (non-clinical), there was a linear relationship on all of these dimensions. More specifically, higher levels of cohesion and adaptability at the family level was associated with better functioning and may be associated with achievement of independence by adolescents reaching young adulthood. Along with young adults’ independence, self care abilities will emerge and the demonstration of health behaviors that will maintain their present health status will become more evident.

One of the factors that will also determine an individual’s health maintenance behaviors is health locus of control (HLOC). The health locus of control construct is derived from Rotter’s (1954) social learning theory. The construct refers to individuals’ control beliefs as it affects their health. Those with internal health locus of control orientation believe that they can control many aspects of their health through their own behavior. Persons with a chance health orientation believe that the control of their health lies with luck, fate, or chance and that there
is little they themselves can do to affect it. Individuals with a powerful others orientation believe that health professionals control health and that regular contact with them and adherence to their orders is the best way to stay healthy (Wallston et al., 1978).

The concept of health locus of control has been incorporated by Pender (1982) into the Modified Health Belief Model originally developed by Becker (1977). This model is currently being used to explain the occurrences of health protecting or preventive behaviors among individuals engaged in self-care activities (see Figure 4). However, since the model illustrates processes related to health prevention it does not accurately reflect the decision making process that leads to health maintenance behaviors in chronically ill adults. Health maintenance behaviors are viewed as different from health prevention behaviors. Health prevention (protection) refers to guarding or defending the individual or group against specific illness or injury by using a set of actions intended to ward off specific illness conditions or their sequelae (Pender, 1987). Health maintenance behaviors refer to a set of behaviors one would carry out in order to maintain his/hers present health status. Thus, health prevention is not a construct that can be used when studying individuals who have had CF most of their life.

Salient dimensions of the model are goal setting on
FIGURE 4. PENDER'S MODIFIED HEALTH BELIEF MODEL

perceived consequences, subjective estimates of desired outcomes, and decision making under uncertainty. As a decision model, the health belief approach reflects social learning theory, Atkinson's views of risk-taking behavior and achievement motivation, and Edward's Behavioral decision theory (Maiman & Becker, 1974).

Components of the model are divided into individual perceptions, modifying factors, and variables that affect the likelihood of initiating action. Individual perceptions directly affect predisposition to take action, while demographic, sociopsychologic, and structural variables act as modifying factors that only indirectly affect action tendencies (Pender, 1982; 1987). Although the model was initially developed for describing determinants of preventive or health protecting behavior, it includes many components that relate to health maintenance behaviors. Pender's (1982) model has been adapted to health maintenance behaviors of chronically ill adults in the following manner (see Figure 5). There are seven perception variables which affect predisposition to engage in preventive behaviors. They are: importance of health, perceived control, perceived threat of specific disease, perceived susceptibility, perceived seriousness, perceived benefits of preventive actions, and perceived value of early detection. Since most patients with CF are usually diagnosed during early childhood, perceived
FIGURE 5. HEALTH BELIEF MODEL OF ADULTS WITH CYSTIC FIBROSIS
susceptibility and perceived value of early detection were deemed inappropriate for adult health maintenance behaviors, and thus were eliminated from the model.

Importance of health has been added to the model by Pender as a measure of general health concern. Although this variable has not been studied much, results of several studies indicate that such a general measure of health concern consistently predicted giving medication and keeping clinic appointment. Suchman (1967) in looking at preventive behavior, also found that concern about health was positively correlated with taking actions to protect health.

Perceived control focuses on the relationship between beliefs about internal-external control and physical health and well being. Internal health locus of control is believed to be the one more conducive to health prevention, and in this case, health maintenance behaviors. Whether perception of control are mediated by ethnic background, socioeconomic status, or patterns of child-rearing has not yet been determined (Pender, 1987). A number of studies have been reported that support the importance of perceived control in predicting the occurrences of preventive behaviors (James et al., 1965; Kirsch, 1972; O'Bryan, 1972).

Perceived threat and perceived seriousness of the illness are intertwined. Understanding of the perceived seriousness of a given condition can be judged either by the
degree of emotional arousal created by the thought of the
disease or by the difficulties that an individual believes a
given health condition would create for him. Perceived
seriousness may include the broad implications of the illness
for work, family life, or social relationships and
commitments (Becker, 1977). A number of studies have shown a
relationship between perceived seriousness and preventive
behaviors, while a few studies have failed to support such a
perceived susceptibility and perceived seriousness combine to
determine the total perceived threat of an illness to a
specific individual. However, for adults with CF, where
perceived susceptibility is not applicable, one’s perceived
seriousness of an illness equals one’s sense of threat by a
chronic illness.

Modifying factors in the model are suggested as
affecting predisposition to take preventive action and they
include a variety of demographic, sociopsychologic, and
structural factors. Although these factors have been studied from a preventive
action perspective, none have been studied from a health
maintenance perspective. In the CF literature age is
correlated with health maintenance behaviors, where there is
a serious decline in following prescribed treatment during
the adolescent years (Donati, et al., 1987) and an increase
of health maintenance behaviors during young adulthood (Kimchi, 1989). Other demographic variables such as sex, income, and education in relation to health maintenance behaviors have not been studied in the adult CF population.

The interpersonal modifying variables include: family-of-origin habitual patterns of care, expectations of significant others, and interaction with health professionals. Although none of these variables have been studied in the adult CF population, a qualitative study conducted by the author as a pilot for this proposed study, offers some insights. In the case where the family-of-origin followed every treatment prescribed by the pulmonologist, the wife took over the role of helping the adult with CF follow each treatment; with an older couple, the husband verbalized his expectations that his wife (with CF) will take good care of herself so that they will be together for many years.

The nature of interactions with health professionals has been shown to affect incidence and consistency of health-protecting behavior (Pender, 1982). In a study of adolescents and young adults with CF, the close and tri-weekly contact of a nurse with the patients was shown to increase their health maintenance behaviors (Donati, et al., 1987). Perception of the level of expertise of health care professionals may also affect predisposition to engage in recommended behaviors. Most CF patients know their
physicians since childhood, however as young adults new relationships of trust and respect have to develop between them, thus, this factor should be considered as a valid modifying variable.

The expectations of significant others concerning health-related behaviors has been supported by the work of Ajzen and Fishbein (1975). They defined normative beliefs as the perceived behavioral expectations of others and motivation to comply with those expectation. In predicting intentions to take part in an influenza immunization program, normative beliefs emerged as a meaningful variable.

Situational variables such as culturally expected health behaviors, reference group norms, and information from non-personal sources, are also suggested as modifying variables. From the young adults interviewed by the author (1989), two women were propelled to follow their prescribed treatment by a book they read which described the life and the process of death of a young woman with CF. One of these women started attending the CF clinic on a regular basis after about a six year absence. Reference group can affect health behaviors by changing attitudes and beliefs or by forcing conformity with group behavior norms. Bond (1965) found that women involved in discussion groups regarding techniques for early detection of breast cancer were more likely to report continued practice of self breast exams than did women who attended
lectures without much opportunity for peer interaction.

The likelihood of action is composed of perceived benefits, perceived barriers, and cues for action. In the model, it is proposed that benefits minus barriers determine the likelihood of taking action, in this case carrying out health maintenance behaviors. Beliefs about the effectiveness of recommended treatment actions are thought to be important determinants of health maintenance behaviors. In the health prevention literature several studies conducted on the relationship between health prevention behavior and belief in effectiveness of treatment showed a positive correlation between the two. For example, women who obtained a pap smear as part of a screening program for cervical cancer were found to believe that the test could detect cervical cancer before appearance of symptoms, and that early detection would lead to a more favorable prognosis (Kegeles, 1969). None of the reviewed studies examined health maintenance behaviors of chronically ill adults.

Perceived barriers for engaging in health maintenance behaviors can take many forms and be perceived or real. Barriers may include cost of care and/or lack of insurance coverage. By the time CF patients reach young adulthood insurance coverage available to them is minimal, and many of their expenses have to be paid out of their pockets. Inconvenience can take many forms, such as the geographical
distance of the CF clinic from patient's home, or his/her inability to attend normal clinic hours while working full time. Extent of life change necessary to engage in health maintenance behaviors may also be a factor as well as the perception of inability to follow through with health recommendations which may be imagined or real. Lack of energy at later stages of the disease and lack of supportive others to help him/her carry out those activities may be other barriers.

Cues to action are proposed as affecting the incidence of health behavior by triggering appropriate overt actions (Pender, 1982). It is speculated that due to the transient nature of cues to action they have not been systematically studied (Pender, 1982). The intensity of cues needed to trigger health maintenance activities given a certain level of readiness to engage in such activities is unknown. The general assumption made when referring to health prevention is that the higher the level of readiness to act, the lower the intensity of the cue needed to trigger behavior. Cues can be either internal or external. An internal cue may be a recall of a previous exacerbation where the patient was very ill, and an external cue may be news on mass media about CF, a death of a close friend or an acquaintance with CF, and awareness of deterioration such as greater shortness of breath when performing certain habitual activities.
Pender’s (1982) model has been critiqued by Wallston and Wallston (1984). They proposed that the model is essentially a catalog of variables rather than a well-articulated model specifying the nature of the relationship among variables. In addition, they point out the lack of consistent operationalization and measurement of the variables across studies. In this proposed study only one variable, health locus of control (HLOC), will be measured using Wallston and Wallston’s (1982) HLOC standardized instrument.

Studying individuals’ health locus of control orientation can be a useless exercise unless some intervention is offered to change it in people with various chronic conditions.

Rosenstock (1975) in his address at the National Heart and Lung Institute Working Conference on Health Behaviors raised the question whether perceptions of interna-external control of health could be changed in adults, and if so, how such changes might be accomplished. Internalization techniques have been suggested in the literature as appropriate for changing individuals’ locus of control orientation.

Internalization techniques include several strategies for changing an external control orientation to a more internal orientation, in an attempt to increase health
behaviors. Arakelian (1980) stresses that in chronic illness, beliefs in control of situations can be beneficial in offsetting adverse emotional responses by focusing on agenda rather than on outcome control.

Measures that have as their prime objective the promotion of increased internality have been identified by MacDonald and Hall (1971). They proposed three approaches: (a) reconstrual of stimuli, (b) action-oriented approach, (c) counseling techniques.

The principle focus of reconstrual of stimuli approach is on helping individuals alter their perception of a particular life situation. Reinterpretation is achieved through discussion; individuals’ outlooks are changed and they are better able to engage in the desired behavior without having changed the situation (Arakelian, 1980). This reorientation might be applicable in situations in which either diagnosis or treatment cannot be changed but the client attitude or interpretation might be altered. A negative event such as burden or stigma could be reinterpreted as a challenge, a means for controlling one’s life affairs, or a potential growth experiences. Finding out client’s health locus of control orientation is a prerequisite for this treatment (Shillinger, 1983).

The action-oriented approach is behaviorally oriented, emphasizing the implementation of new behaviors rather than
the alteration of attitudes. Essentially, this approach involves problem-solving skills that externally oriented individuals may have not mastered simply because they do not see themselves as change agents. Presumably, once individuals learn how to effect the necessary changes in their behavior and see how these new actions change life events, belief in an internal locus of control is enhanced (Arakelian, 1980).

The counseling approach allows individuals to recognize contingencies between their behaviors and outcomes by considering past, present, and future events; alternative actions; and the consequences of various behavior choices (Arakelian, 1980). In the case of clients holding external control expectancies, these could be cognitively linked with old successes (Lefcourt, 1966).

In a study by Keller et al (1985) a sample of 5 adults with CF ages 19 to 41 years participated in a six-week stress management and life-style modification program. The program consisted of discussions on life-style topics and stress management techniques both behavioral and cognitive. The effects of the program on their physical and psychological well-being were measured. One of the measuring instruments was the health locus of control scale. At the end of the program an increase in internal control was noted for the participants which indicated that they began to rely more on
their own judgment in health-related issues, thus acknowledging themselves as playing a more important role in the maintenance of their health. However, there was also an increase in the powerful others subscale which might indicate an increased trust in health professional following the treatment program.

It is hoped that by employing internalization techniques to change one’s health locus of control, from external to internal, number of health maintenance behaviors performed will increase. In summary, young adults with CF might experience difficulties in maintaining their health due to hindered individuation process during adolescence in their chaotically enmeshed or rigidly enmeshed families (strict control, little independence for individual members), and consequently, the development of a non-internal health locus of control orientation. Internalization techniques may be used to attempt to alter their health locus of control orientation which hopefully will increase the number of their health maintenance behaviors. Lack of health maintenance behaviors may have deleterious affects on their physical health status and their prognosis.
CF is the most common genetic disease in Caucasian populations, with an incidence of 1 in 2,000 live births and a carrier frequency of approximately 1 in 20 (Murphy, 1987). The incidence in the nonwhite population is significantly lower (1 in 17,000) in American blacks and 1 in 90,000 in Hawaiian Orientals. The disease has been reported rarely in native Americans and Chinese (Cutting, 1990). CF occurs in equal numbers in males and in females. The disease is inherited as an autosomal recessive trait. Heterozygotes suffer none of the symptoms of cystic fibrosis and at present, there is no practical method for detecting cystic fibrosis carriers in the general population (Davis & diSant’Agnese, 1984).

Cystic fibrosis was first recognized as a separate clinical and pathological entity in 1938. CF has since been regarded as a congenital familial fatal disease. Seventy five percent of the patients then died within their first year of life, and more than 95% within the next three years (Anderson & Hodges, 1946). The median age of survival of these patients has improved, from 7 years in 1968 to 24 years in 1985. An adult population of cystic fibrosis patients has now emerged. Currently there are many young adults with CF
approaching 30 years of age in many CF centers. However, females tend to have less favorable survival records past puberty in comparison to males (Rosenstein, 1989). The improved prognosis is being attributed to: earlier diagnosis; diagnosis of milder, previously undiagnosed patients; vaccines; more effective and aggressively administered antibiotics; earlier and more aggressive nutritional intervention; and a specialized team approach to patient management (Rosenstein, 1989).

Cystic fibrosis is characterized by viscous secretions obstructing the exocrine glands. The organs most affected are the lungs, pancreas, small intestines, sweat glands, liver, and the reproductive system. The organ dysfunction leads to chronic pulmonary disease, pancreatic insufficiency, abnormal sweat electrolytes, biliary cirrhosis, and decreased fertility.

The treatment program in general use today was outlined by Matthews et al in 1964. It included secretion removal, antibiotics, vitamin and pancreatic enzyme supplement. New recent trends of care include long-term use of aerosolized antibiotics which have been associated with improved pulmonary function (Hodson et al., 1987; Jensen et al., 1987) and decreased hospitalization rate (Wall et al., 1983). The use of home IV antibiotics has been shown to be less costly, less stressful and as effective as in-hospital therapy in selected patients (Donati et al., 1987; Gilbert et al., 1988). Recently, the CF gene has been localized to a region on the long arm of chromosome 7. On the basis of DNA sequence analysis, the CF gene product is predicted to be a
transmembrane protein with properties similar to a number of other proteins involved in transport functions (thus named CF Transmembrane Conductance Regulator or CFTR) (Collins, 1991). The identification of the gene has potential importance for early diagnosis, genetic engineering, treatment, and total eradication of the disorder (Colten, 1988).

**Physiological Profile of young adults with CF**

Pulmonary complications dominate the clinical picture in young adults with cystic fibrosis (CF) (Murphy, 1987). Symptoms are recurrent and progressively disabling and body organs deteriorate as the person becomes older. The organs in which clinical abnormalities have been documented most in CF are the airways, pancreas, and sweat glands. The basic defect in CF is expressed in epithelial cells and is manifest phenotypically by failure of chloride secretions to occur across the apical surface of epithelia in response to physiologic regulation. The epithelium in which this defect has maximal clinical impact is respiratory epithelium, for most patients with CF succumb to airway disease (Davis, 1990). This basic physiologic defect predisposes the airways to chronic infection with recurrent exacerbation and associated tissue inflammation that results in progressive deterioration of pulmonary function. The lungs may be normal at birth but soon afterward they become obstructed with thick mucous secretions. While the volume of secretions is normal,
the viscosity is increased, which results in markedly decreased airflow to the lungs. Viscous secretions trap bacteria which proliferate and establish airway infection and inflammation results. The earliest manifestation of pulmonary dysfunction in CF is an abnormality in the distribution of ventilation, resulting in increased alveolar-arterial oxygen differences that may occur before any detectable change in flow rates or lung volumes. Earliest pulmonary function changes show reduced maximal expiratory flow rate at low lung volumes (Murphy, 1987). As the disease progresses, large airway obstruction becomes more manifest, with decreased in maximal midexpiratory flow and FEV1 (forced expiratory volume in the first second). The manifestations of the chronic pulmonary disease include bronchitis, broncholitis, and bronchopneumonia. A state of acute and chronic infection and inflammation develops and damaged parynchemal lung tissue is then replaced by fibrous tissue. The fibrous tissue tends to aggravate the pulmonary disease by further obstructing small airways. Patients with cystic fibrosis have chronic coughing with wheezing and they suffer hypoxia. In the later stages, hypercapnia ensues, with accompanying pulmonary hypertension and cor pulmonale. Cor pulmonale is occurring with increasing frequency as the patients live longer. When right sided congestive heart failure develops, the prognosis is poor (Huang et al., 1987). Heart-lung or lung transplantations are recognized as an innovative procedure for individuals with pulmonary disease and combined cardiac/pulmonary failure. The prognosis of persons with CF is directly related to the severity of their
pulmonary disease. More than 90% of the mortality in CF is due to pulmonary complications (Berkin et al., 1985; Huang et al., 1987; Quinton, 1990).

Infection plays an important role in the symptomatic exacerbations of the pulmonary disease and in the progressive destruction of the lungs in patients with CF whereas bronchospasm and alveolar obstruction are only minor components. Therefore, therapy is based on the principles of relief of bronchial obstruction and combating infection (diSant’Agnese & Davis, 1984).

Staphylococcus aureus (S. aureus) and Pseudomonas aeruginosa (P. aeruginosa) are the pathogens most frequently associated with pulmonary disease in patients with cystic fibrosis. S. Aureus is found in the early stages of the pulmonary disease, before antibiotics have been given; it can usually be controlled by antibiotics. Then P. aeruginosa becomes the leading pathogen. Approximately 64% of all cystic fibrosis patients have P. aeruginosa in their sputum. The organism causes recurrent purulent bronchitis and can damage lung tissue via exotoxins and various proteases (Lewison, 1989). The local immune response of the patient with inflammation, release of WBC proteases, is increasingly recognized as important in this process.

Patients with CF often have mucoid variants of P. aeruginosa that are rarely seen in individuals with other chronic respiratory diseases. The reason for the presence of this mucoid strain so selectively in CF patients is not clearly understood but appears to be related to virulence. The mucoid material produced makes the microorganisms
difficult to phagocytize and provides an effective barrier against antibiotics. It is thought that the inability of CF patients to respond to mucoid P. aeruginosa with an effective immune response underlies in part the persistence of the infection (Pier, 1990). Recently, new strands of Psuedomonas cepacia (P. cepacia) that are resistant to multiple drugs have presented a difficult problem in clinical management and a new threat to longevity in persons with CF (Huang et al., 1987). Curiously, only certain organisms are able to colonize the CF respiratory tracts: S. aureus, Hemophilus influenza, P. aeruginosa and P. cepacia. (Lewison, 1989). Pseudomonas infections in CF patients, unlike those in other patients, rarely cause septicemia and usually show little systemic response such as fever, toxic appearance, etc. However, despite improved oral and I.V. antibiotic treatment, chronic pulmonary damage secondary to progressive pseudomonas aeruginosa infection still accounts for 99% of all deaths (Durie & Forstner, 1990). Low clinical score, low weight percentile, and Psudomonas cepacia colonization of the lower respiratory tract at the age of 18 years indicate a poor prognosis. On the other hand, high clinical score, good weight percentile, and colonization with Staphylococcus aureus alone were likely to be found in patients with mild disease and an increased likelihood of long-term survival with preserved pancreatic function (Huang et al., 1987).

In adults, as in children, the combination of chronic obstructive pulmonary disease (COPD) and intestinal malabsorption is characteristics of almost all patients. However, with advancing age, symptoms due to pancreatic
insufficiency appear to diminish, whereas COPD increasingly dominates the clinical picture. There are also important differences in the relative incidence of various complications so that the manifestations of CF in adults are quite different from those in children (diSant'Agnese & Davis, 1979). These authors (1979) examined a data base of 307 adults comprised of 75 clinic patients and 232 cases reported in the literature. COPD, present in 97% of all patients, was the major cause of morbidity and mortality, and differed from COPD of other etiologies. The progressive downhill course in these patients was punctuated by recurrent symptomatic exacerbations of chronic bacterial bronchitis caused by Pseudomonas aeruginosa and Staphylococcus aureus, and terminated in pulmonary insufficiency, cor pulmonale, and death. COPD was complicated by minor hemoptysis in 60%, massive hemoptysis in 7% and pneumothorax in 16%, problems rare in children (diSant'Agnese & Davis, 1979).

Spontaneous pneumothorax has been reported to occur in 19% of CF patients over 14 years of age. Pneumothorax develops from the rupture of subpleural air cysts and bullae through a pleura weakened by postinflammatory changes. Despite the successful treatment of pneumothorax, the prognosis for survival is poor because of the severity of the underlying lung disease. The mean survival of 15 patients with pneumothorax in one series was 3.4 years after the initial episode (DeBoeck & Zinmon, 1984; Spector, 1990).

Hemoptysis occurs when a blood vessel within a bronchiectatic area of the lung is eroded by infection/inflammation. Blood streaked sputum is common in
older persons with CF and usually can be managed conservatively without progression. The origin of this bleeding is usually a small tear of mucosa from an infected bronchus. Massive hemoptysis usually arises from erosion into a bronchial artery and is a serious and potentially life-threatening complication. Massive hemoptysis is usually identified by expectoration of 300 to 500 ml of blood in 24 hours and may be accompanied by a decrease in hematocrit and orthostatic blood pressure changes (Stern et al., 1978).

As with the lungs, the pancreas also shows progressive deterioration with age. The ducts of the pancreas appear to obstruct with inspissated secretions. Luminal obstruction and dilation of the secretory acini and ducts seem to be followed by atrophy and degeneration of the exocrine parenchyma (Durie & Gorstner, 1990). Pancreatic insufficiency occurs in 85%-95% of CF patients. The pancreatic ducts are obstructed by mucous secretions and are therefore unable to release digestive enzymes into the duodenal fluid. Because of the obstruction, proteins, lipids, and starches are not degraded into simple molecules suitable for absorption. Autodigestion of the pancreas occurs, resulting in fibrotic lesions. Untreated patients suffer steatorrhea, foul-smelling stools and malnutrition. In addition, the fat-soluble vitamins - A, D, E, and K- are not absorbed properly and vitamin deficiency can occur. The treatment for pancreatic insufficiency includes a high-protein, high-calorie diet, accompanied by pancreatic enzyme and vitamin supplements. Even with treatment, the patient may appear malnourished and underdeveloped because of excessive calories expended in work
of breathing or coughing and due to the infections load (Durie & Gorstner, 1990). The endocrine pancreas appears to survive this destruction remarkably well, although the incidence of glucose intolerance increases with age. As a consequence, young adults with CF are faced with the possibility of acquiring additional chronic conditions such as diabetes mellitus. Recent studies suggest incidence levels as high as 8% to 15% with evidence for glucose intolerance to be present in as high as 40% to 60%. This increased prevalence appears to be a consequence of the increased life expectancy and it is anticipated that the number of patients with both CF and diabetes mellitus will continue to increase (Zipf, 1990).

Not all patients with CF have pancreatic insufficiency (PI) which is characterized by clinically apparent symptoms of maldigestion. An important subset of CF patients do not exhibit steatorrhea, some of whom may even secrete enzymes within the normal range (Durie & Forstner, 1990). These "pancreatic sufficient" patients enjoy much milder symptoms, with better respiratory function, fewer gastrointestinal complications and a better overall prognosis than the patients who have PI. It is now being suggested that the clinical differences in disease expression between CF patients with and without pancreatic sufficiency are a direct result of genetic factors (Durie & Forstner, 1990).

The sweat gland only infrequently causes a clinical problem, which is usually in the form of hypovolemia due to salt loss associated with heat prostration. The abnormally high salt concentration of sweat is so characteristic and
consistent that it is the cornerstone of differential diagnosis. In CF, sweat production and volume are normal, but it contains from three to five times the normal concentration of NaCl. Potassium is also increased, but to a lesser extent. Unlike the lungs and the pancreas, the sweat glands are not altered by secondary morphological changes; consequently these glands provided the first compelling evidence of an inherent disturbance in fluid transport. There is no correlation between the severity of the disease and the degree of sweat electrolyte abnormality.

These three organs, the lungs, pancreas and sweat glands, present the historically recognized trilogy of pathological expressions uniquely characteristic of CF. However, much evidence exists for related abnormalities in many other exocrine epithelial systems such as the liver.

As treatment of CF patients has increased life expectancy, the morbidity and mortality in CF patients from liver disease has become more prevalent (Roy et al, 1982). Focal biliary cirrhosis (FBC) and the more severe multilobular biliary cirrhosis (MLC) are considered pathognomonic of CF. The bile ducts become blocked with eosinophilic material and the blockage causes biliary cirrhosis and secondary portal hypertension. Both have an increasing incidence with age, and of the adolescent/young adults population, up to 40% will develop FBC and 10% MLC (Gaskin et al., 1990). Liver transplantation is accepted as the treatment of choice for end-stage liver disease and mild-moderate pulmonary involvement (Mieles, 1989).

The gastrointestinal tracts (GI tracts) are also
affected. Viscid secretions in the GI tract obstruct exocrine and excretory ductal structures, leading to inflammatory obliteration and fibrosis of the affected ducts and dysfunction of the proximal tissues. Intestinal malabsorption and inadequate oral intake in the climate of recurrent pulmonary infections often culminates in generalized malnutrition and specific nutrient deficiencies. The goals in managing CF patients include prevention of GI and nutritional problems, early recognition of specific organ or nutrient abnormalities, and education of patient and family regarding the importance of nutrition and the GI tract for the well-being of young adults with CF (Sokol, 1990).

Young adults with CF suffer from malnutrition secondary to pancreatic insufficiency and chronic lung disease (Berkin et al., 1985; Huang et al., 1987). A deficiency of pancreatic potases, lipases/colipase and amylase, in approximately 85% of the patients with CF may contribute to maldigestion of dietary nutrients. By adulthood, the symptoms of foul smelling stools, flatus, and fatty food intolerance, characteristics of children and adolescents with CF, is more controlled and the need for dietary restrictions may decrease, however, malabsorption may continue (Lapey et al., 1974). Malabsorption, decreased oral intake and hypermetabolism contribute to the overall energy deficit of adults with CF (Pencharz, 1990). The high energy requirements of adults with CF due to increased respiratory effort and energy cost of recurrent infections, are well appreciated and it is now clear that there may be an association between nutritional and pulmonary status (Gaskin
et al., 1990). Huang et al (1987) found that weight was closely associated with low clinical score, P. cepacia colonization and short duration of survival. Aggressive nutritional management with oral, enteral, and parenteral support has been associated with improved growth and clinical status, and fewer pulmonary infections. The currently recommended diet consists of high protein, high calorie diet with no restrictions on fat intake. Liberalization of fat intake has been associated with improved prognosis (Corey, 1980). Approximately 80-130 kcal per kg per day with 2.5 to 3 gm of protein is recommended.

The prevalence of intestinal obstructive complications of CF increases with age, occurring in about 17 percent of the adult CF population. These obstructive episodes are thought to result from a combination of incomplete digestion, abnormal intestinal gland secretions, and abnormal fluid and electrolyte transport in the intestines. Thus, the fecal stream is semisolid instead of liquid. Inspissated feces adhere to the bowel wall, causing inflammation and serving as a lead point for intussusception or as an accumulation point for more fecal material, leading to impaction. Intestinal problems such as distal intestinal obstruction syndrome is more common in adolescents and adults (Kopelman, 1990).

The gall bladder is abnormal in 1/3 of patients. Fecal bile acid losses and thickened mucus cause gallstones, seen in 5% of older patients. Gallbladder abnormalities occur in 40 to 50 percent of CF patients, with cholelithiasis occurring more frequently in adults (Sokol, 1990).

Musculoskeletal problems are a common additional cause
of morbidity in adults with CF (Douglas et al., 1990). Some patients suffer classical pulmonary hypertrophic osteoarthropathy, which causes pain and affects mobility adversely.

Physical appearance of the young adult with CF is also altered by the disease. Many have short stature, esthenic appearance with barrel chests, and are underweight. Digital clubbing has been shown to be present in almost all adults with CF (DeBoeck & Zinmon, 1984). Clubbing results from hypertrophy of connective tissue in the nail beds of the fingers and toes. Nasal polyps have been reported in 48% of adults with CF (DeBoeck & Zimon, 1984). Nasal polyps may be asymptomatic or may cause rhinorrhea, pain, or epistaxis progressing to complete nasal obstruction. Distortion of facial appearance may result from severe polyps, with depression and widening of the nasal bridge. The exact etiology is unknown. Young adults with CF have to deal with recurrent pulmonary exacerbations of the illness. The underlying cause of exacerbations is unknown, and thus it may happen at any time. The exacerbation is a clinical state with increased cough and sputum production often associated with a darkening in sputum color, and increased respiratory rate. The exacerbation may be associated with weight loss, low grade fever, increased rales or rhonchi on auscultation, worsening of pulmonary function and, occasionally, new infiltrates on the chest radiograph.

Since young adults with CF constitute a new population even their treatment is controversial. There is controversy over the use of antibiotics for CF. Some recommend
prophylactic antibiotics, while others feel that antibiotics are most beneficial during acute respiratory infections and that more chronic use may select resistant bacterial strains. Antibiotics may alleviate those symptoms but they will not eradicate the Pseudomonas. Treatment of the pulmonary disease also includes physical and respiratory therapy to clear excessive mucous from the lungs (Fick & Stillwell, 1989). Physical therapy in the form of postural drainage with percussion, has been a mainstay of CF treatment, yet few objective data have been produced to assess the long term benefits of this inconvenient, time consuming therapy (DeBoeck & Zinmon, 1984). Chest physiotherapy with postural drainage has been shown to acutely improve pulmonary function and stopping chest physiotherapy for a 3-week period caused a decline in lung function that was reversed when therapy was resumed (DeBoeck & Zinmon, 1984). Routine chest physiotherapy demands time and effort and compliance is poor with this therapy. Other controversial treatments are the use of bronchodilators and mucolytics; the method by which antibiotics should be administered orally, by nebulizer or intravenously; use of corticosteroids; and hospital utilization in emergent and nonemergent situations.

Young adults with CF have to deal with issues of infertility. Ninety eight percent of males with CF have azoospermia. During development, the vas deferens becomes blocked with viscid material and atrohyes. Thus the body and the tail of the epididymis and the seminal vesicles are abnormal or absent. It is not known why this embryonic defect occurs in CF. Spermatogenesis is present but because
of the mechanical obstruction, no live sperms appear in the ejaculate. Anatomically, the female reproductive tract is normal but the cervical mucus is abnormally thick with decreased water content. The thick cervical secretions can inhibit sperm penetration and thus results in decreased fertility. However, women with CF are capable of conception, but many are advised against it since pregnancy tends to contribute to a deterioration of pulmonary status (Davis & diSant’ Agnese, 1984). Even oral contraceptive therapy has been reported to have an effect on pulmonary function in CF, and female CF patients using them need to have a close follow up of pulmonary function (Buhlmann et al., 1990). In addition, cervicitis, cervical erosions, and mucous gland hyperplasia in the cervix is common. In instances where persons with CF were able to parent children, the possible abandonment of their offsprings at a young age, is a cruel reality.

In summary, young adults with CF are faced with many issues that did not exist prior to the last two decades. Concerns regarding serious physical complications such as respiratory failure, pneumothorax, and cirrhosis of the liver, dominate the lives of young adults with CF. The disease progressively disables their bodies so that they have to essentially approach diminishing activity at a young age. Treatment remains supportive in the absence of identification and correction of the basic underlying mechanism, but a combination of judicious and energetic management of the various aspects of the disease can help these patients achieve a good quality of life.
Health Locus of Control

The concept of internal versus external control of reinforcement developed out of social learning theory (Rotter, 1954; Rotter, Chance, & Phares, 1972). Social learning theory is a theory of personality that attempts to integrate two diverse but significant trends in American psychology - the stimulus-response, or reinforcement theories on the one hand and the cognitive, or field, theories on the other. It is a theory that attempts to deal with the complexity of human behavior.

There are four classes of variables in social learning theory: behaviors, expectancies, reinforcements, and psychological situations. In its most basic form, the general formula for behavior is that the potential for a behavior to occur in any specific psychological situation is a function of the expectancy that the behavior will lead to a particular reinforcement in that situation and the value of that reinforcement.

According to Rotter (1966), individuals will engage in goal-directed behavior only if they value the particular reinforcers available and if they believe that their actions will lead to these reinforcers in a particular situation. Individuals' consistent beliefs and perceptions, which influence behavior in various situations, are referred to
theoretically as generalized expectancies. Such expectancies are considered independent of the value or importance of the reinforcer. One generalized expectancy, internal versus external control of reinforcement (I-E), refers to the extent to which an individual feels that he/she has control over the reinforcers that occur relative to his/her behavior (Rotter, 1966). Internals feel they are effective agents in determining the occurrences of rewards. Externals, however, tend to believe that forces beyond their control (fate, luck, chance, powerful others, or the complexity of the world) determine the occurrence of reinforcement.

Since the development of Rotter's (1966) Internal-External (I-E) scale, numerous investigators have used locus of control, or a modified version of it, to relate this psychological construct to health behavior. In one of the first studies conducted by Seeman and Evans (1962) it was demonstrated that persons who were higher on internality were more knowledgeable about their disease and its management. Most findings since then have confirmed these earlier results (Strickland, 1979). Persons with internal locus of control (internals) were more actively involved, more autonomous in their decision making, and able to make better use of relevant information to promote health than persons with higher external scores (externals). For example, persons with higher internal locus of control were more likely to be
nonsmokers than smokers (James et al., 1965), more likely to be users of contraceptives (Phares, 1968), and more likely to complete weight reduction programs and lose more weight (Balch & Ross, 1975) than those with external locus of control orientation. In the study of locus of control among alcoholics, recovering alcoholics, and non-alcoholics, the non-alcoholic group scored more internally than the other two groups; the recovering alcoholics scored more internally than the alcoholic group (Huckstadt, 1987).

Glugut, et al (1986) studied the relationship between locus of control orientation and subjects' response to a plaque control program. Subjects who believed that their susceptibility can be controlled by their own actions (internals) responded more positively to the program.

Individual beliefs about control over their health were assessed in 47 patients with spinal cord injury. Patients who believed they exercised control over their health were less depressed than patients who were fatalistic. A significant number of these patients were found to be higher in their internal attributions of health control (N=31) than those who believed in chance (N=5) and those who believed medical personnel were in control of their health (N=11) (Frank & Elliott, 1989).

Nagy and Wolfe (1983) used the MHLC scales in a study of illness symptoms and satisfaction with medical treatment
among 250 chronically ill male patients. High scores on the internal scale were predictive of fewer illness symptoms, and higher satisfaction was positively related to higher powerful others scores. Other investigators have found patients with chronic, unpredictable illnesses (i.e. rheumatoid arthritis, cancer) perceived less personal control over their illness than patients with more medically controllable illnesses (i.e. hypertension, diabetes) (Felton & Revenson, 1984; Felton et al., 1984). These findings imply that health attributions vary with type and chronicity of condition.

Analysis of data from a year-long study of 1210 adults responses to illness episodes revealed that a sense of low control (as measured by the Internal-External scale) was significantly associated with more illness, had greater dependency on the physician, had less self-directed preventive care, and was less optimistic about the efficacy of early treatment (Seeman & Seeman, 1983).

The basic assumption that health locus of control beliefs contribute to the prediction of health behavior was also supported by Kerr (1986) who examined the relationships between health locus of control beliefs of workers with hypertension, adherence to antihypertensive regiments, and diastolic blood pressure levels. Workers who scored high on the chance dimension were the least successful in lowering their diastolic blood pressure.
The effectiveness of patient controlled analgesia (PCA) in 76 female patients who underwent abdominal gynecological procedures revealed that internal locus of control was predictive of lower pain scores and increased satisfaction. On the other hand, patients with external locus of control had higher levels of pain and greater dissatisfaction with PCA (Johnson et al., 1989).

In a sample of 178 newly diagnosed patients with breast cancer, non-Hodkin’s and Hodgkin’s lymphomas, lower psychological morbidity was associated with a positive/confronting response to diagnosis and with high internal locus of control, while higher anxiety and depression scores were associated with a hopeless-helpless response to diagnosis and with low internal locus of control (Burgess et al., 1988).

In a study by Weerdt et al (1990), determinants of active self-care behaviors of insulin treated patients with diabetes, were examined. Results showed that attitude along with a low orientation on the powerful others health locus of control scale, were the prerequisite for having a positive attitude about their illness. They concluded that diabetes education, among other goals, should focus of improving patients’ internal health locus of control orientation.

The examination of health locus of control orientation in joggers versus non-exercisers revealed that joggers scored
significantly higher on the internal subscale than did the nonexercisers. No significant differences were found on the chance or powerful others subscales (Slenker et al., 1985).

In an Australian study, Meize-Grochowski (1990) examined the relationship between health locus of control and glycosylated hemoglobin concentration on implantable insulin pump recipients. Using Wallston and Wallston (1982) classification, most patient (N=30) were classified as ‘believers in control’, however, correlation with blood glucose level was insignificant.

In studies on smoking behaviors, James Woodruff and Werner (1965) found that non-smokers were more likely to be internal in their locus of control orientation than were smokers. In addition, they found that persons who believed in the health damaging effects of smoking and had quit were more internal than were individuals who believed that smoking was hazardous to health but did not quit.

In another study, Platt (1969) (cited in Pender, 1982) found internally controlled individuals able to change smoking behaviors to a greater extent than were externally controlled individuals. Kaplan and Cowels (1978) found in a study of 35 participants in a smoking cessation program that health locus of control and health values emerged as important variables in predicting smoking cessation.

A number of studies that support the importance of
perceived control in predicting the occurrence of preventive behaviors, have been reported. Kirscht (1972), in exploring the relationship between locus of control, perceived susceptibility to illness, and perceived benefits of preventive act, found that those who were internally controlled viewed themselves as less susceptible to illness and identified preventive measures as more efficacious than did externally controlled individuals. Age was significantly correlated with perception of control, with younger individuals believing that they exerted more control over health than did older persons. Women believed that they had more control over health than did men.

While some of the studies support the importance of health locus of control (as a determinant of smoking behavior), some studies have failed to show this association (Best & Steffy, 1971).

Health locus of control (HLOC) has been explored also in relation to weight and weight loss. Manno and Marston (1972) found, in their control group, that externally oriented subjects weighed more initially but lost more weight; thus, among control group subjects, internals were more successful. However, for their two treatment groups there was no relation between HLOC and weight loss.

O'Bryan (1972) found overweight women to be more external. Balch and Ross (1975), in using a self-control
weight reduction program, found significant correlation between internality and completion of the program, and internality and success of the program (achievement of weight loss greater than the median).

The importance of HLOC has been supported also in studies of use of birth control, seat belt use, preventive dental care, and the likelihood of obtaining immunization for influenza.

Most of the studies used health locus of control as a predictor variable for health promoting activities but not for health maintenance behaviors. The statistical analyses most often performed were correlational in nature and the variance in health behavior that could have been explained by HLOC, was not calculated. Health locus of control was examined using the following outcome measures: Healthy internals and some internals with various health problems exhibited less depression, fewer illness symptoms, higher satisfaction with treatment, had lower pain scores, lost the most weight, and were the non-smokers, joggers and non-alcoholics. In the same samples, externals exhibited more illness manifestations, greater dependency, less self-directed preventive care, felt less optimism and were least successful in lowering blood pressure and losing weight.

The only study to include persons with CF was a comparison between children with CF and children with asthma.
Steinhausen (1988) found no correlation between HLOC and degree of illness. Children with CF did have a more external LOC scores than did asthmatic children. No additional studies were found in the literature on the health locus of control of adults with CF. Factors that may affect HLOC, such as religion and socioeconomic status, were mentioned in the literature. According to Levin and Schiller (1986) religious affiliation affects one's health locus of control orientation. In a sample of adults (N=909), in a self-care health education program in Appalachia, the highest internal scores were among Mormons (29.5), Episcopalians (29.3), and Catholics (28.4). The highest powerful others score was among Presbyterians (22.7), adherents to a tradition founded in reverence to "presbyters" or powerful church elders. Subjects reporting no affiliation had the lowest powerful other score (16.5).

MacDonald (1971) presented several research studies that indicated that social disadvantage and minority group membership are conducive to the development of external control orientation. The claim is based of the tenet that many socially disadvantaged persons do not try to better their circumstances largely because of low expectancy for success. These factors have been incorporated into the demographic questionnaire used in this study.

In summary, most of the studies indicated that
internality was positively associated with health prevention behaviors. The studies were conducted with mostly healthy subjects, and very few used chronically ill patients. However, since health prevention behaviors are closely related to health maintenance behaviors, as conceptualized in beginning of chapter 2, health locus of control seems to be an appropriate construct for studying health maintenance behaviors of young adults with CF. Findings of most of the studies seem to support the fact that HLOC may be an important factor in predicting health behaviors and that it should also be taken into consideration in tailoring preventive measures to individual health locus orientation.

**FACES III and the Circumplex Model**

FACES III was developed to assess the major dimensions of the Circumplex model and has been utilized in many studies. However, very few studies used chronically ill adults in their samples.

A study by Clark (1984) focused on families with schizophrenics, neurotics, families who had therapy sometime in their past, and a no-therapy control group. In general, he found a very high level of extreme families in the neurotic and schizophrenic groups compared to the no-therapy
group. Conversely, he found a significantly higher level of balanced families in the no-therapy group compared to the other groups.

Several studies in which the original FACES instrument was used focused on alcoholic families in which the identified patient was the mother or father. Olson and Killorin (1984) found significant differences between chemically dependent families and nondependent families, and as hypothesized, alcoholic families had a significantly higher level of extreme families compared to the nondependent family.

In the study by Carnes (1985), FACES II was used to investigate family systems in sex offenders. He found high levels of extreme family types in both their family of origin and their current families. While about half (49%) had extreme family types in their family of origin and about two-thirds (66%) of their current families were extreme types, only 19% of the nonoffender families were extreme. Conversely, while only 11% of their family of origin and 19% of their current families were balanced types, about half (57%) of the nonoffender families were balanced.

Comparing 27 high risk families with 35 low risk families, Gabarino et al (1985) focused on their type of family systems using FACES II. Using intact families, both parents and one adolescent completed FACES II and a variety
of other scales that were used to assess family stress, parenting, and family conflict. As hypothesized by the Circumplex model, they found that the majority of the low risk families were balanced type (mainly flexibly connected) while the majority of the high risk families were an extreme type (mainly chaotically enmeshed).

In the study by Rodick et al (1986), 29 mother-son dyads from father-absent families with an adolescent juvenile offender were compared to father-absent families with adolescents with no history of arrest or psychiatric referral. Only 7% of the families with delinquent children were balanced while 93% of them were mid-range or extreme types. In contrast, 69% of the nondelinquent families were balanced while 31% were mid-range or extreme.

Studies that examined family of origin of adults with CF were not found in the literature. However, one study used FACES III in studying families of children with CF. Lewis and Khaw (1982) who hypothesized that healthy adjustment in the child with CF is more dependent upon healthy family functioning (balanced levels of cohesion and adaptability) than on the mere presence of the illness, found a significant \( (F=7.76, \ p=0.001) \) relationship between extreme family functioning and the number of behavior problems reported in the eighty four children 7-12 years old.

In summary, these studies of clinical samples
clearly demonstrate the discriminant power of FACES and the Circumplex model in distinguishing between problem families and nonsymptomatic families. There is strong empirical support for the hypothesis that balanced types of families are more functional than extreme family types. There is, however, a lack of evidence that any of these symptoms are specifically linked with a specific type of family system, for example, chaotically enmeshed.

In contrast to the curvilinear relationship found on these dimensions of problem families, there appears to be a linear relationship between cohesion and adaptability in family functioning of "normal" families. More specifically, higher levels of cohesion and adaptability seem to be associated with better family functioning. These results were found in the national survey with 1,000 families across the life cycle, which was reported by Olson and colleagues (1983). A primary reason for this finding is that normal families represent only a narrow spectrum of the range of behavior on these two dimensions. As a result, there are very few of the "normal" families that legitimately fall into the extreme types (Olson, 1986).
CHAPTER III

Research Design

The design of this study was ex post facto. Two independent variables (health locus of control and family-of-origin type) and one dependent variable (health maintenance behavior) in young adults with cystic fibrosis (CF) and healthy young adults were measured. Ex post facto design has been defined as a systematic empirical inquiry in which the scientist does not have direct control of independent variables because their manifestations have already occurred or because they are inherently not manipulable (Kerlinger, 1973). Inferences about relations among variables are made, without direct intervention, from concomitant variation of independent and dependent variables (Kerlinger, 1973).

The two independent variables of health locus of control and type of family of origin have already occurred and were not manipulable, thus the use of ex post facto design in this study, was judged to be appropriate.
Subject Selection

Two subject groups were chosen for this study: a group with cystic fibrosis (CF) and a comparison group of healthy individuals. The CF group was selected by a criterion sampling and consisted of 235 patients with CF, from 10 Midwestern CF centers. The sample of healthy individuals was a convenience sample of 202 healthy volunteers who were drawn from various classes in a large Midwestern university.

The participating CF centers were: Ann Arbor, Michigan; Cincinnati, Ohio; Columbus, Ohio; Dayton, Ohio; Iowa City, Iowa; Lexington, Kentucky; Madison, Wisconsin; Milwaukee, Wisconsin; Minneapolis, Minnesota; Pittsburgh, Pennsylvania. Institutional Review Board (IRB) approvals were granted from the Ohio State University and all participating institutions except Cincinnati, Dayton, and Milwaukee, Wisconsin, where IRB approvals were not required (•) (see Appendix B).

Criteria for subjects' selection for the CF group were: (a) between 18-28 years of age and diagnosed as having CF (b) no evidence of mental deficiency as judged by the pulmonologist and the clinic nurse, (c) able to read and write English, (d) Pulmonary function test results of FEV1 between 42%-80% predicted and FVC between 50%-89% predicted, (e) patient's condition clinically evaluated by the pulmonologist as good, mild, or moderate. FVC and FEV1 are the most common specific pulmonary function measurements conducted in all CF centers. FVC is a lung volume measurement which provides information concerning air trapping. FVC is that volume of gas that can be expired as
forcefully and rapidly as possible after maximal inspiration. FEV₁ is a flow measurement which assesses the extent of obstruction caused by mucous plugging, bronchospasm and edema. FEV₁ is the volume of gas expired over one second during the performance of FVC. By assessing the flow at a specific interval (one second), the severity of airway obstruction can be ascertained by comparing it to norms reporting it as percent predicted for the patient's height and sex (Chernick & Kendig, 1990). The most recent values of FEV₁ and FVC for each patient were obtained from each center. The cut-off points for Forced Vital Capacity (FVC), (Taussig et al, 1973) were set at:

- 71% - 89% of predicted - Good
- 61% - 70% of predicted - Mild
- 50% - 60% of predicted - Moderate

Forced Expiratory Volume at first second (FEV₁), (Taussig et al, 1973) were set at:

- 70% - 80% of predicted - Good
- 58% - 69% of predicted - Mild
- 42% - 57% of predicted - Moderate

Since much variability existed between FEV₁ and FVC values, and there is no method to combine both scores into a composite score, it was decided to use only one of these measures. FEV₁ was chosen as the indicator of patients' illness severity based on the fact that it provides information about the extent of the pulmonary obstruction. Also, one may have a low FEV₁ and still maintain a fairly high FVC thus, FEV₁ seemed more indicative of illness severity than FVC. In the initial stage of sample selection
it was decided to not include in the study patients that were either extremely ill with compromised health status, or in excellent condition who usually have very little manifestations of the disease. However, as the study progressed, it was discovered that each CF center and its pulmonary lab use different formulas to calculate FEV1. Since all the initial criteria for selection based on FEV1 and FVC were in percent predicted values, all the raw scores (in liters) for each patient were obtained from the corresponding centers. The FEV1 figures were then recalculated at the Pulmonary Lab at Columbus Children's Hospital using the Morris et al (1971) formula (See Appendix C) for patients 18 years of age and older. Three patients in the sample were 17 years of age and the combined formula of Dickman, Schmidt and Gardner (1971) was used to calculate their FEV1 values. As a result of the recalculation of the FEV1 values, 31 patients who initially were within the predetermined cut-off points set at the start of the study, had values lower than the lowest cut-off point of FEV1 of 42% ranging from 21% to 40% (indicates severe pulmonary obstruction), and 14 subjects had values above the upper limit of the cut-off points (80%) ranging between 81% and 115% (indicates excellent pulmonary function). Several FVC values also were changed by the recalculation, so that 17 patients moved below the lower limit ranging from 34% to 49% (indicates severe pulmonary obstruction) and 19 patients moved above the upper limit ranging from 90% to 137% (indicates excellent pulmonary function). It was decided to keep these patients in the study and the data was analyzed by
the initial severity of illness cut-off points for good, mild and moderate. The data was also analyzed according to five levels of illness severity to account for the individuals with extreme low and high scores. The two new FEV1 cut-off points were: 21-40 poor and 81-115 excellent. The two new FVC cut-off points were: 34-49 poor and 90-101 excellent. There were no differences in the analysis using three categories or five categories of illness severity.

The sample of 202 healthy subjects was obtained from three university courses with a mix of undergraduate and graduate students, at a large Midwestern university: a psychology class (n=88), an engineering class (n=26), and a human ecology class (n=40). Response rate was 100%. No incentives or inducements were offered to the students. Criteria for inclusion in this sample were: (1) between the ages of 18-28, (2) no chronic illness or condition, (3) able to read and write English.

Forty eight individuals were excluded from the analysis for either being outside of the age range of 18-28, having a chronic illness or completing the whole questionnaire without answering the question of whether or not they have a chronic illness.

A power analysis for a sample of 100 patients in each group yielded a medium effect size with a power of at least .94 in each of the planned statistical analyses with an alpha of .05 (Table 1). The power was calculated for the group factor, thus the two levels of group (CF and healthy), with an estimated sample size of 100, and effect size of 0.50. Medium effect size refers to the quantified effect of the
independent variable on the dependent variable, with a probability of .94 of rejecting the null hypothesis when it is indeed false. A medium effect will make a noticeable difference. A power level of .94 is considered "very good" (Nunnally, 1978).

Table 1 - Power Analysis

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number</th>
<th>N Per Level</th>
<th>Degrees Freedom</th>
<th>Effect size (in SD units)</th>
<th>Power</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor A</td>
<td>2</td>
<td>100.0</td>
<td>1</td>
<td>0.500</td>
<td>0.940</td>
</tr>
</tbody>
</table>

A power calculation was also performed for the correlational analyses. According to Cohen (1977), a sample of 100 will be able to detect a minimum correlation of .30 with power of .86 and 2 tailed alpha of .05, if it is a true correlation.

Instruments

Five instruments were used in this study. The Multidimensional Health Locus of Control (Wallson, et al., 1978), Form A was used to measure individuals' health locus of control; the Cantril Ladder (Andrews & Withey, 1976) which provided the respondents' perceived health status on day of
questionnaire completion. FACES III (Olson, et al., 1985), the ideal and the real forms, were utilized to map out subjects' family-of-origin types; the demographic information sheet which provided descriptive data about the participants, and the Health Maintenance Behavior form which measured the number of health maintenance behaviors each subject carried out on a regular basis. Copyright permissions were obtained where needed (see Appendix E).

The Multidimensional Health Locus of Control Scale (MHLC)

The MHLC instrument was developed by Wallston, Wallston, and DeVellis (1978), and it was used to measure Pender's Perceived Control portion of her Modified Health Belief Model. The Multidimensional Health Locus of Control (MHLC) is an 18 item, 6-point Likert scale (Wallston et al., 1978). This instrument allows a measure on internal, powerful others and chance scores. Each of the questions is designed to determine how people view certain health-related issues. The respondents indicate on a likert scale from 1 to 6 whether they strongly disagree (1) to strongly agree (6) with the belief statement. Alpha coefficients of the MHLC scales range from .67 to .77 in prior studies (Wallston et al., 1976; 1978). The internal scale reliability reported previously by Wallston was .71 to .77, powerful others .67 to .72 and chance scale .69 to .75. Differences in health behaviors can be predicted from MHLC cluster membership (Rock et al., 1987). Normative data on adults are available
(Wallston & Wallston, 1981). The MHLC is a two-part measure of perceptions of health control in two different forms. Use of both forms yields more reliable data than use of either alone. With the use of one form only, the alpha reliability coefficient is .67 - .77; when two forms are used, the alpha reliability coefficient increases to .83 - .86 (Wallston et al., 1978). However, the investigator had opted for using Form A only, since using both forms would have made the questionnaire too long and was likely to decrease response rate.

In subsequent studies (Wong & Sproule, 1984; Wallston & Wallston, 1982) reliability of the MHLC was found to be somewhat lower than that found by Wallston et al (1978).

In the Kerr (1986) study the three-dimensional health locus of control orientation accounted for 8.6% of the variance in improvement of diastolic blood pressure levels in hypertensive clients. While this does not appear to be a very large percentage, Seeman and Seeman (1983) caution that one should not expect that locus of control would "capture a large percentage of the share of the variance regarding health" in view of the large number of other factors believed to contribute to health actions and outcomes.

The three MHLC subscales are empirically independent, and the Internal and Chance scores are negatively correlated and the Chance and Powerful Others scale have a low correlation of 0.20 (Wallston & Wallston, 1981). Cronbach Alpha coefficient for this study (Table 2) were similar to those obtained by Wallston and Wallston (1976). Concurrent and discriminant validity were established by correlating the
MHLC scales with Levenson’s scales (Levenson & Miller, 1976). The MHLC sub-scales correlated most highly with their theoretical counterpart on the Levenson instrument: Internality (.43), Powerful Others (.37) and Chance (.59).

**TABLE 2**

Health Locus of Control - Internal Consistency

<table>
<thead>
<tr>
<th>Subscales</th>
<th>Cronbach Alpha</th>
<th>Cronbach Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kimchi (1992)</td>
<td>0.83</td>
<td>0.76</td>
</tr>
<tr>
<td>Wallston, et al, (1978)</td>
<td>0.72</td>
<td>0.75</td>
</tr>
<tr>
<td>(N=297)</td>
<td>0.70</td>
<td>0.67</td>
</tr>
</tbody>
</table>

Several sources noted that contradictory evidence has accumulated on the validity and internal consistency of the subscales. In research that employed samples of medical and dental students (Winefield, 1982), college students (O’Looney & Barrett, 1983), cigarette smokers (Coelho, 1985), alcoholics (Russell & Ludenia, 1983), and rehabilitation patients (Umalauf & Frank, 1986), subscales intercorrelations and factor analysis did not support a clear distinction between subscales Powerful others and Chance, thus
questioning the multidimensionality of the instrument. Internal consistency reliability, measured by Cronbach's alpha coefficient, has been reported to be as low as .49 for the Chance and .58 for Powerful others (Winfield, 1982). The internal scale consistently has been demonstrated to be stable and homogeneous. Each person ends up with three different scores, one on each of the subscales. Low scores on the internal scale do not mean that individuals believe that external factors determine their health; all that can be said about low scores is that they are not indicative of internal beliefs. The higher the score on the internal subscale, the more personal control clients believe that they exercises over their own health. The higher the score on the chance subscale and powerful others subscales the higher the beliefs in the importance of chance and others respectively in controlling personal health. Normative means for adults on each subscale are as follows: internal - 50.4; chance - 31.0; powerful others - 40.9 (Wallston et al., 1978).

The scale was scored as follows: the score on each subscale is the sum of the values circled for each item in that subscale. Internal items: 1, 6, 8, 12, 13, 17
Chance items: 2, 4, 9, 11, 15, 16
Powerful others items: 3, 5, 7, 10, 14, 18

The Cantril Self-Anchoring Ladder

This Cantril self-anchoring scale is an interval type
instrument on which respondents mark a point that describes their present health status on a range from 1, worse health I can imagine, to 10, best health I can imagine. It provided a base-line of the individual’s perceived health status at time of questionnaire completion. The validity coefficient for this measure is .73 (Andrews & Withey, 1976). Reliability lies within the individual response since it is self-anchoring and totally subjective. Test-retest reliability is not appropriate since it is a “state-related” instrument.

FACES III

FACES III is an acronym for Family Adaptability and Cohesion Evaluation Scales. FACES III assess family cohesion and family adaptability, the two major dimensions on the Circumplex model, and enables the researcher to place families within that model. It is intended to be administered to families across the life cycle. The items reading level is sixth grade. FACES III is designed to obtain both perceived and ideal family functioning. The perceived-ideal discrepancy provides an inverse measure of family satisfaction. The larger the discrepancy score the more dissatisfied they are about their family. The instrument is easy to administer and simple to score. It can be administered on an individual basis, and may be used in mailed surveys. It consists of two scales, 20 perceived and 20 ideal item. Normative sample N=2453 adults across the life cycle. Reliability: internal consistency for cohesion
is \( r = .77 \) and for adaptability \( r = .62 \), total reliability of \( r = .68 \). Test retest reliability (4-5 weeks) \( .83 \) for cohesion and \( .80 \) for adaptability. Cronbach Alpha coefficient for this study were higher in all subscales (Table 3).

| TABLE 3 |
|---|---|
| **FACES III- Internal Consistency** | |
| **Subscales** | **Cronbach Alpha** | **Chronach Alpha** |
| | (N=297) | N=2412 |
| Cohesion-Real | 0.92 | 0.77 |
| Cohesion-Ideal | 0.92 | 0.77 |
| Adaptability-Real | 0.77 | 0.62 |
| Adaptability-Ideal | 0.75 | 0.62 |

Face validity and content validity of FACES III are very good. The two dimensions assessed by this instrument have been independently identified by various theorists who claim that these dimensions are critical for understanding family systems. Also therapists and researcher have determined that in terms of face validity, the instrument meets acceptable criteria (Olson, 1982). Correlation between cohesion and adaptability is \( r = .03 \) which is very low. Correlation of
adaptability with social desirability is \( r = 0.00 \). Empirical studies using the FACES instrument have consistently shown an ability to discriminate between clinical and nonclinical families (Olson et al., 1985). These studies clearly demonstrated the discriminant power of FACES and the Circumplex Model in distinguishing between problem families and non-symptomatic families (Bonk, 1984; Rodick, et al., 1985).

The 20-item scale contains 10 cohesion items and 10 adaptability items. There are two items for each of the following five concepts related to the cohesion dimension: emotional bonding, supportiveness, family boundaries, time and friends, and interest in recreation. There are two items for each of the concepts related to adaptability dimensions: leadership, control, and discipline; and four items for the combined concept of roles and rules. The respondents were asked to read the statements and decide for each one how frequent, on a scale that ranges from 1 (almost never) to 5 (almost always), the described behavior occurred in his/her family.

Each participant was instructed to complete the perceived form and the ideal form as it related to their family of origin. The scale was used to map out family-of-origin type of each participant. Family of origin were classified into one of the 16 types of the Circumplex Model. The participants completed the perceived form as to how they see their family of origin which gave a sense of what was their family like when they were growing up. By completing the ideal form the participants indicated how they would have
liked their family of origin to have been. The information from the perceived form was used to typify the family-of-origin. Each family was plotted onto 16 types of families (Figure 6). The data was also divided into three groups of families: balanced, midrange and extreme.

Cystic Fibrosis - Health Maintenance Behaviors

A nominal scale of activities performed by individuals with CF for maintenance of their health status, which includes questions about prescribed treatments as well as general activities such as exercises. The list is based on clinical literature, clinical experience and a pilot study. Content validity was established by the CF center director who is a pulmonologist and by a CF clinic nurse. This instrument was not administered to the comparison group. The comparison group was not asked about any health behaviors for two reasons: (a) Healthy individuals would not engage in any health maintenance behaviors similar to those necessitated when one has CF, thus there was no way to compare between the two group on that variable. (b) Health behaviors of young adults are usually carried out for health promotion or health prevention reasons, however, the health behaviors of young adults with CF are performed in order to maintain their present level of health, which are two different constructs (see operational definition section).

The health maintenance behaviors questionnaire was divided to two sections: physical activity and behaviors
related to the CF condition. Physical activities were scored (Sport score) as follows: 1 point for each activity performed once a week, occasionally or seasonally; 2 points were given per activities carried out twice a week; 3 points were given for activities performed 3 times a week or more. Maximum points for the total instrument - 24 points. Internal consistency of the instrument was measured by Cronbach alpha which yielded a coefficient of 0.492. Alpha level was not going to increase with a deletion of any item. The Cronbach’s alpha is low because the items of this instrument were not suppose to correlate. The instrument is a nominal list of different physical activities, that any healthy or ill person, might perform.

The Health Maintenance Behavior instrument is also a nominal list of all health related activities that persons with CF might perform. The instrument was scored (Behavior Score) as follows: activities were divided to respiratory related behaviors (maximum 40 points), nutrition related behaviors (maximum 30 points), and diabetes related activities (maximum 4 points). Each activity received 10 points, except for glucose monitoring and taking hypoglycemics which received 2 points each. If the activity was performed without a doctor’s order, 2 more points per activity were added. Activities performed on a PRN basis were given 5 points. Total maximum points for the instrument - 76 points.

Internal consistency of the instrument (behavior score only) was measured by a Cronbac’s alpha and showed a coefficient of 0.480. Deletion of any item would not have
improved the alpha level. It is to be expected that the Cronbach’s alpha is low since the items in this instrument are not expected to correlate highly with each other.

**Demographic Information Sheet**

Provided descriptive information on the sample characteristics such as age, sex, birth order, age at diagnosis, siblings with CF, marital status, living arrangements, place of residence, ethnic background, occupation/profession, employment status, hours of work per week, yearly income, highest educational degree, educational status, number of siblings with CF, psychologic/psychiatric counseling in the past year, and number of hospitalization days during the past year.

**Procedure**

A request for participation was sent to each center along with a copy of the proposal and supporting documents. A follow-up phone call was made a week later. Participation was invited from 12 centers, ten center directors agreed to take part in the study. Two centers declined participation due to their own ongoing studies. Each center director was then asked to designate a nurse or another health professional to help in forming a list of appropriate patients. Institutional review board applications were completed by the investigator.
for each center that requested it; approvals from all these centers were granted (see Appendix B).

Subject inclusion criteria were mailed to each center. The contact person in each center formulated a list of prospective participants which included patient's name, address, date of birth, FEV1 and FVC values. Envelopes containing the survey booklet, a consent form, a support letter from the corresponding CF center director, a self-addressed-stamped envelope and a tea bag with a thank you note, was mailed to each center. Envelopes were coded consecutively and by center, for example, LK1, LK2, indicated the Lexington Kentucky CF center, patient number 1 and patient number 2. The code was written in three places: on the left lower corner of the mailing envelope, on the left lower corner of the return envelope, and on the back of the booklet. The contact person at the corresponding centers assigned the provided code on her patients list, and mailed the envelopes. Each contact person kept the code list for the second mailing and any future correspondence regarding the patients. The coded list was then mailed to the investigator without patient names. This was the procedure in centers where the IRB requested that patients' identity not be made known to the principal investigators. In other centers, where this was not a requirement, the investigator mailed the surveys directly to the subjects. Only one center agreed to mail a precard informing the subjects of the forthcoming questionnaire. All the responses were mailed directly to the principal investigator. Dillman's (1978) Total Design Method was used in preparation of the survey
booklet and mailings. There were only two mailings: the initial one and one follow up. The booklets for the second mailing were mailed approximately three weeks after the first mailing. The center directors did not agree to more than one follow up mailing. The returned envelopes were monitored by their color: return envelopes of the first mailing were white and the return envelopes for the second mailing were brown. Return rates varied by centers ranging from 33% to 100%. The return rate was 47% for the first mailing and 26% for the second mailing. Return rate for the total study was 62%.

Limitations of the Study

There are several limitations to this study. Data collected from subjects on past familial behavior is self-reported and thus relies on recall. This data can be inaccurate due to perceptual changes and biases over time. In addition, the answers provided by the respondents in regard to their family of origin may reflect their current emotional needs, rather than the reality as they were growing up.

Internal health locus of control was the measured orientation of 83% of the individuals in both groups. Due to this high percentage of respondents with internal HLOC, the comparisons between individuals with internal, chance or powerful others orientation was limited, and might have affected the results of this study.

Pender’s modified health behavior model was not tested in its entirety, only several components were examined:
perceived control, perceived barriers to action, and modifying factors such as demographics, proximity to CF clinic, and family of origin. Consequently, the findings of this study should be interpreted with caution in light of the possibility that testing the whole model would have changed the results.

Generalizability of the findings extends only to other CF patients seen in clinics in Midwestern states and those seen periodically by a pulmonologist. Findings may not apply to other CF patients in other geographical areas because care there may be different. Generalizability may also be affected by the limited comparison between respondents and non-respondents. Although no significant statistical differences were found between the two groups, the comparison was performed only on age and physical status.

The population is self-selected and the particular health condition is very specific. However, in view of these limitations, significant findings may still be generalizable to a substantial CF population residing in the Midwest and treated by a CF clinic pulmonologist.

**Data Analysis**

Descriptive, parametric and non-parametric statistics were used to describe the sample. Chi-square, t-test, Pearson's Correlations, and analysis of variance were used to analyze the data using the computer program CRISP. BMDP was
used for the stepwise logistic regressions. Cronbach Alpha coefficient were used to analyze the internal consistency of the data collection instruments.
CHAPTER IV

Analysis of the Data

Description of the Sample

There were 297 respondents in this study. Of these, 154 (51.9%) were in the comparison group of healthy individuals (group 1) and 143 (48.1%) were individuals with cystic fibrosis (group 2). Ninety seven percent of the comparison group and 100% of the CF group were white. Comparative demographic characteristics of these two groups are presented in Tables 4-7. The two groups were very close in age with a mean age of 21.93 (SD=1.98) for the healthy group and 22.84 (SD=3.27) for the group with CF. The healthy group consisted of approximately one-third males and two-thirds females. They were primarily single (83.8%), living in a metropolis or a large city with a roommate (46.1%) or with one or both parents (24.4%). Parents of 22% of the sample lived less than 50 miles away, and parents of 61.1% of the sample lived more than 100 miles away. The majority of the group (72.7%) was employed and worked between 10-30 hours per week, usually in a job that did not require physical labor. Two-thirds of the sample did not have an occupation. Those individuals that did work were involved in office-related occupations or
<table>
<thead>
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<th>Characteristic</th>
<th>Frequency (%)</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Healthy</td>
<td>N = 154</td>
<td>Individuals with CF</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>43 (28)</td>
<td>60 (42)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>111 (72)</td>
<td>83 (58)</td>
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</tr>
<tr>
<td>Marital Status</td>
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<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>129 (83.8)</td>
<td>92 (64.3)</td>
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<tr>
<td>Married</td>
<td>18 (11.7)</td>
<td>40 (28)</td>
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<td>Divorced</td>
<td>1 (0.6)</td>
<td>7 (5)</td>
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<tr>
<td>Separated</td>
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<td>1 (0.7)</td>
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<tr>
<td>Cohabiting</td>
<td>6 (3.9)</td>
<td>3 (2)</td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christian</td>
<td>87 (56.5)</td>
<td>73 (51.8)</td>
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</tr>
<tr>
<td>Catholic</td>
<td>44 (28.6)</td>
<td>43 (30.5)</td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>6 (3.9)</td>
<td>1 (0.7)</td>
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</tr>
<tr>
<td>Muslim</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Buddhist</td>
<td>1 (0.6)</td>
<td>1 (0.7)</td>
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<tr>
<td>None</td>
<td>12 (7.8)</td>
<td>12 (8.5)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>4 (2.6)</td>
<td>11 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (4)</td>
<td>13 (9)</td>
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</tr>
<tr>
<td>No</td>
<td>148 (96)</td>
<td>129 (91)</td>
<td></td>
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<tr>
<td>Child Was</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Naturally Conceived</td>
<td>6 (100)</td>
<td>12 (75)</td>
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<td>Adopted</td>
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<td>1 (6)</td>
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<tr>
<td>Artificial Insemination</td>
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<td></td>
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<tr>
<td>Step Child(ren)</td>
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<td>2 (13)</td>
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TABLE 5. LIVING ARRANGEMENTS

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<th>Frequency (%)</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Healthy</td>
<td>Individuals</td>
<td>Individuals with CF</td>
</tr>
<tr>
<td></td>
<td>(N = 153)</td>
<td>(N = 141)</td>
<td>(N = 140)</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolis (over 100,000)</td>
<td>58 (37.9)</td>
<td>22 (15.6)</td>
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</tr>
<tr>
<td>City (50,000-100,000)</td>
<td>57 (37.3)</td>
<td>31 (22)</td>
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<tr>
<td>Small City (10,000-50,000)</td>
<td>20 (13)</td>
<td>34 (24.1)</td>
<td></td>
</tr>
<tr>
<td>Town (2,500-10,000)</td>
<td>6 (3.9)</td>
<td>24 (17)</td>
<td></td>
</tr>
<tr>
<td>Small Town (under 2,500)</td>
<td>3 (2)</td>
<td>12 (8.6)</td>
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</tr>
<tr>
<td>Rural (but not a farm)</td>
<td>8 (5.2)</td>
<td>17 (12)</td>
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<tr>
<td>On a Farm</td>
<td>1 (0.7)</td>
<td>1 (0.7)</td>
<td></td>
</tr>
<tr>
<td>Living With</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>By Yourself</td>
<td>19 (12.3)</td>
<td>19 (13.6)</td>
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<tr>
<td>One or Both Parents</td>
<td>37 (24.1)</td>
<td>55 (39.3)</td>
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<tr>
<td>Spouse</td>
<td>19 (12.3)</td>
<td>37 (26.4)</td>
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<tr>
<td>Roommate</td>
<td>71 (46.1)</td>
<td>20 (14.3)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8 (5.2)</td>
<td>9 (6.4)</td>
<td></td>
</tr>
<tr>
<td>Parent(s) Distance</td>
<td>[Rest Live with Parent(s)]</td>
<td>[Rest Live with Parent(s)]</td>
<td></td>
</tr>
<tr>
<td>(N = 118)</td>
<td>(N = 86)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less Than 50 Miles</td>
<td>26 (22)</td>
<td>54 (62.8)</td>
<td></td>
</tr>
<tr>
<td>More Than 50 Miles</td>
<td>20 (16.9)</td>
<td>6 (7)</td>
<td></td>
</tr>
<tr>
<td>More Than 100 Miles</td>
<td>42 (35.6)</td>
<td>9 (10.5)</td>
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<tr>
<td>More Than 200 Miles</td>
<td>14 (11.9)</td>
<td>7 (8.1)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>16 (13.6)</td>
<td>10 (11.6)</td>
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TABLE 6. EMPLOYMENT

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (%)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Healthy</td>
</tr>
<tr>
<td></td>
<td>individuals</td>
</tr>
<tr>
<td>Employment</td>
<td>(N = 154)</td>
</tr>
<tr>
<td>Yes</td>
<td>112 (72.7)</td>
</tr>
<tr>
<td>No</td>
<td>42 (27.3)</td>
</tr>
<tr>
<td>Occupation</td>
<td>(N = 54)</td>
</tr>
<tr>
<td>1. Teacher</td>
<td>8 (14.8)</td>
</tr>
<tr>
<td>2. Security Officer</td>
<td>6 (11.1)</td>
</tr>
<tr>
<td>3. Health Care Field</td>
<td>3 (5.6)</td>
</tr>
<tr>
<td>4. Engineer/Technician/Designer</td>
<td>5 (9.3)</td>
</tr>
<tr>
<td>5. Office Work</td>
<td>15 (27.8)</td>
</tr>
<tr>
<td>6. Housewife/Nanny/Child Care</td>
<td>10 (18.5)</td>
</tr>
<tr>
<td>7. Maintenance Work</td>
<td>1 (1.8)</td>
</tr>
<tr>
<td>8. Waitress/Hostess/Chef</td>
<td>6 (11.1)</td>
</tr>
<tr>
<td>9. No Occupation</td>
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<tr>
<td>10. Computer Work/Accountant/Lab</td>
<td>0</td>
</tr>
<tr>
<td>11. Musician/Artist</td>
<td>0</td>
</tr>
<tr>
<td>12. Farmer</td>
<td>0</td>
</tr>
<tr>
<td>Length of Employment</td>
<td>(N = 114)</td>
</tr>
<tr>
<td>Less Than 1 Year</td>
<td>57 (50)</td>
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<tr>
<td>Less Than 2 Years</td>
<td>21 (18.5)</td>
</tr>
<tr>
<td>More Than 2 Years</td>
<td>19 (16.7)</td>
</tr>
<tr>
<td>More Than 3 Years</td>
<td>12 (10.5)</td>
</tr>
<tr>
<td>More Than 4 Years</td>
<td>2 (1.7)</td>
</tr>
<tr>
<td>More Than 5 Years</td>
<td>2 (1.7)</td>
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<tr>
<td>Other</td>
<td>1 (0.9)</td>
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TABLE 6. (Continued)

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<tr>
<th>Characteristic</th>
<th>Frequency (%)</th>
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<tr>
<td></td>
<td>Healthy</td>
<td>Individuals with CF</td>
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<tr>
<td></td>
<td>Individuals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(N = 116)</td>
<td>(N = 95)</td>
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<tr>
<td>Work Hours Per Week</td>
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<tr>
<td>Less Than 10 Hours</td>
<td>11 (9.5)</td>
<td>6 (6.3)</td>
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<tr>
<td>10-20 Hours</td>
<td>44 (37.9)</td>
<td>15 (15.8)</td>
</tr>
<tr>
<td>20-30 Hours</td>
<td>37 (31.9)</td>
<td>9 (9.5)</td>
</tr>
<tr>
<td>30-40 Hours</td>
<td>8 (6.9)</td>
<td>29 (30.5)</td>
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<tr>
<td>More Than 40 Hours</td>
<td>10 (8.6)</td>
<td>21 (22.1)</td>
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<tr>
<td>Hours Vary</td>
<td>2 (1.7)</td>
<td>9 (9.5)</td>
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<tr>
<td>Work Summers Only</td>
<td>4 (3.5)</td>
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<tr>
<td>X Work Hours Per Week</td>
<td>20-30 Hours</td>
<td>30-40 Hours</td>
</tr>
<tr>
<td>Job Requires Physical Work</td>
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</tr>
<tr>
<td>(N = 120)</td>
<td>(N = 95)</td>
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</tr>
<tr>
<td>Yes</td>
<td>28 (23.3)</td>
<td>25 (26.3)</td>
</tr>
<tr>
<td>No</td>
<td>92 (76.7)</td>
<td>70 (73.7)</td>
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<tr>
<td>&quot;Bad&quot; Work Environment</td>
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<tr>
<td>(Not Asked)</td>
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<tr>
<td>Yes</td>
<td>42 (44.2)</td>
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<td>No</td>
<td>53 (55.8)</td>
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### TABLE 7. INCOME AND EDUCATION

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<tr>
<th>Characteristic</th>
<th>Healthy Individuals</th>
<th>Individuals with CF</th>
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<tr>
<td>1990 Income</td>
<td>(N = 125)</td>
<td>(N = 125)</td>
</tr>
<tr>
<td>Less Than $10,000</td>
<td>105 (76.6)</td>
<td>76 (60.8)</td>
</tr>
<tr>
<td>$10,000-$14,000</td>
<td>16 (11.7)</td>
<td>13 (10.4)</td>
</tr>
<tr>
<td>$15,000-$19,999</td>
<td>9 (6.6)</td>
<td>19 (15.2)</td>
</tr>
<tr>
<td>$20,000-$24,999</td>
<td>4 (2.9)</td>
<td>12 (9.6)</td>
</tr>
<tr>
<td>$25,000-$29,999</td>
<td>2 (1.5)</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>$30,000-$39,999</td>
<td>1 (0.7)</td>
<td>4 (3.2)</td>
</tr>
<tr>
<td>Highest Educational Degree</td>
<td>(N = 154)</td>
<td>(N = 132)</td>
</tr>
<tr>
<td>8th Grade</td>
<td>1 (0.6)</td>
<td>0</td>
</tr>
<tr>
<td>10th Grade</td>
<td>1 (0.6)</td>
<td>2 (1.5)</td>
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<tr>
<td>High School Diploma or Equivalency</td>
<td>107 (69.5)</td>
<td>76 (57.6)</td>
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<tr>
<td>Associate, Two Year, Junior College Degree</td>
<td>13 (8.5)</td>
<td>25 (19)</td>
</tr>
<tr>
<td>Bachelor's Degree</td>
<td>26 (17)</td>
<td>25 (19)</td>
</tr>
<tr>
<td>Master’s Degree</td>
<td>4 (2.6)</td>
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<tr>
<td>Doctorate</td>
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<td>0</td>
</tr>
<tr>
<td>Professional (MD, DDS, etc.)</td>
<td>1 (0.6)</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (0.6)</td>
<td>1 (0.7)</td>
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<tr>
<td>Current Educational Status</td>
<td>(N = 154)</td>
<td>(N = 143)</td>
</tr>
<tr>
<td>Full Time Student</td>
<td>96 (62.3)</td>
<td>52 (36.4)</td>
</tr>
<tr>
<td>Part Time Student</td>
<td>5 (3.3)</td>
<td>14 (9.8)</td>
</tr>
<tr>
<td>Not a Student</td>
<td>0</td>
<td>74 (51.7)</td>
</tr>
<tr>
<td>Other</td>
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<td>3 (2.1)</td>
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<tr>
<td>Student (time not known)</td>
<td>53 (34.4)</td>
<td>0</td>
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</table>
were involved in some form of child care. The majority (76.6%) had an income of less than $10,000 a year, and 98.8% had a high school education or higher. The group of the individuals with CF consisted of 42% males and 58% females. Only 64.3% were single and more of them were married (28%) than in the comparison group (11.7%). Their place of residence was divided between all the categories. Only 14.3% lived with a roommate but 39.0% lived with one or both parents. Three times as many parents of the CF subjects (62.8%) lived less than 50 miles away from them than did parents of the individuals in the comparison group. Only 30% lived more than 100 miles away from their parents. The majority of the subjects (65.9%) were employed and worked between 30 to more than 40 hours a week in a job that usually did not require hard physical work. Their occupations varied, but the highest percentage of any category had office work (23%). The majority of the sample (76%) had less than $10,000 yearly income, and 98.5% had a high school education or a higher degree. Both groups had approximately the same number of bachelor and professional degrees. More individuals from the CF group (19%) held a two year associate degree than in the healthy group (8.5%).

Sample Characteristics Associated with having CF

The following information was collected from the CF group only and compared to national data provided by the CF
Foundation for 1990.

The CF group, 143 individuals, weighed between 80-170 pounds with a mean weight of 121 pounds (S.D.=22.16), median weight was 122 pounds. Their height ranged between 60-75 inches with mean height of 65.6 inches (S.D.=3.46), median 65.0. A third of the sample was diagnosed at birth, 52% were diagnosed between ages 1-4 years. Mean age at diagnosis was 2.5 years (S.D.=3.53) which is the same as the national data (S.D.=8.2) (CF Foundation, 1990). One third of the sample had a sibling with CF: 22% had one sibling, 8% had two siblings. A third of the sample were the oldest child in their family, 40% were the youngest, 17% were middle children.

Half of the subjects visited their CF clinic 2-4 times a year. Average of 4.3 visits per year (S.D.=3.6) which is similar to national data (CF Foundation, 1990) of 4.4 average visits per year (S.D.=3.5).

Except for visiting their pulomonologist at the CF clinic, 58.7% did not make any other doctor visits in matters related to their CF condition. However, 18% made one or two visits, mean visits 1.76 (S.D.=3.4), range 1-25 visits.

In regard to physical complications, about half of the group (54.5%) experienced hemoptysis, 18.9% had diabetes mellitus, 7% were diagnosed of having liver abnormality, 6.3% had cor pulmonale, and 3% experienced a pneumothorax in the past two years.

The subjects were also asked if they have ever had
specific types of surgeries. Sinus surgery was the most common (27.3%) followed by abdominal (18.9%), tubal ligation (5.6%), and pulmonary surgery (3.5%). About 12% percent of the sample had intestinal obstruction.

In summary, the characteristics of this sample of individuals with CF seems similar to those reported by the Cystic Fibrosis Foundation.

Research question #1

What is the health maintenance behavior profile of young adults with cystic fibrosis?

Performance frequency of twelve health maintenance behaviors that individuals with CF are supposed to carry out on a daily/weekly basis were obtained by the Health Maintenance Behaviors instrument. Results are summarized in Table 8. The most frequent activities were taking enzymes (90.9%) and taking vitamins (87.4%). Aerosols and postural drainage, which are the most recommended activities for preservation of pulmonary function, were only performed by 72.7% and 58% respectively. Various physical activities young adults with CF carried on a weekly basis (termed: sports score) are described in Table 9. The most common physical activity performed three or more times a week was walking (51%) followed by weight training (18.9%), other activities (16.8%), and biking (9.8%). The other activity
### TABLE 8. HEALTH MAINTENANCE BEHAVIORS - CF GROUP (N = 143)

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aerosols</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>37 (25.9)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>104 (72.7)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td><strong>Postural Drainage</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>59 (41.3)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>83 (58.0)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td><strong>Night Time Oxygen</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>139 (97.2)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>4 (2.8)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>0</td>
</tr>
<tr>
<td><strong>Take Enzymes</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>12 (8.4)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>130 (90.9)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td><strong>Oral Nutritional Support</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>100 (69.9)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>42 (29.4)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td><strong>Home IV Therapy</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>135 (94.4)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>6 (4.2)</td>
</tr>
</tbody>
</table>
TABLE 8. (Continued)

(N = 143)

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tube Feedings</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>141 (98.6)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>0</td>
</tr>
<tr>
<td><strong>Take Vitamins</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>18 (12.6)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>125 (87.4)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>0</td>
</tr>
<tr>
<td><strong>Oral Bronchodilators</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>83 (58.0)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>56 (39.2)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>4 (2.8)</td>
</tr>
<tr>
<td><strong>Antibiotics</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>49 (34.3)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>81 (56.6)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>13 (9.1)</td>
</tr>
<tr>
<td><strong>Monitor Glucose</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>122 (85.3)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>19 (13.3)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td><strong>Take Hypoglycemics</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121 (84.6)</td>
</tr>
<tr>
<td>Yes - weekly</td>
<td>22 (15.4)</td>
</tr>
<tr>
<td>Yes - when needed</td>
<td>0</td>
</tr>
<tr>
<td>Activity</td>
<td>Frequency (%)</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------</td>
</tr>
<tr>
<td><strong>Aerobics</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>108 (75.5)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>13 (9.1)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>13 (9.1)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>9 (6.3)</td>
</tr>
<tr>
<td><strong>Biking</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>103 (72.0)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>22 (15.4)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>4 (2.8)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>14 (9.8)</td>
</tr>
<tr>
<td><strong>Gardening</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>122 (85.3)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>16 (11.2)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>3 (2.1)</td>
</tr>
<tr>
<td><strong>Hiking</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>122 (85.3)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>17 (11.9)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td><strong>Hunting</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>124 (86.7)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>15 (10.5)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>3 (2.1)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>1 (0.7)</td>
</tr>
</tbody>
</table>
TABLE 9. (Continued)

(N = 143)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Jogging</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>121 (84.6)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>11 (7.7)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>6 (4.2)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>5 (3.5)</td>
</tr>
<tr>
<td><strong>Skiing</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>124 (86.7)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>17 (11.9)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>0</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>2 (1.4)</td>
</tr>
<tr>
<td><strong>Swimming</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>102 (71.3)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>29 (20.3)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>6 (4.2)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>6 (4.2)</td>
</tr>
<tr>
<td><strong>Walking</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>34 (23.8)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>25 (17.5)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>11 (7.7)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>73 (51.0)</td>
</tr>
<tr>
<td><strong>Weight Training</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>98 (68.5)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>11 (7.7)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>7 (4.9)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>27 (18.9)</td>
</tr>
</tbody>
</table>
TABLE 9. (Continued)

(N = 143)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>95 (66.4)</td>
</tr>
<tr>
<td>Once/week or occasionally</td>
<td>14 (9.8)</td>
</tr>
<tr>
<td>Twice/week</td>
<td>10 (7.0)</td>
</tr>
<tr>
<td>Three or more times/week</td>
<td>24 (16.8)</td>
</tr>
</tbody>
</table>
category included activities such as bowling, dancing and basketball. Among the most common activities performed once a week, occasionally, or on a seasonal basis were swimming (20.3%), walking (17.5%), biking (15.4%), hiking (11.9%), skiing (11.9%), and gardening (11.2%). Less than 10% engaged in aerobic exercises. Twice a week for any physical activity did not seem to be a favorite option. Less than 10% of the sample chose this option for any physical activity. Except for walking, at least 65% of the sample for each activity, did not do that activity. The distribution of the sport scores were as follows:

<table>
<thead>
<tr>
<th>Range</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No physical activity</td>
</tr>
<tr>
<td>1-6</td>
<td>Low physical activity</td>
</tr>
<tr>
<td>7-12</td>
<td>Moderate physical activity</td>
</tr>
<tr>
<td>13-18</td>
<td>Good physical activity</td>
</tr>
<tr>
<td>19-24</td>
<td>High physical activity</td>
</tr>
</tbody>
</table>

The majority of young adults with CF were either low or moderate on their physical activity. Only 6.9% did not do any physical activity. The reasons most often mentioned for lack of physical activity were: being too busy or having jobs that involved much walking such as respiratory therapist in a hospital setting, waitresses, students having to walk between
classes, and mothers of toddlers.

In summary, the most typical health maintenance behaviors profile of young adults with CF seems to include taking daily enzymes and vitamins but performing aerosols and postural drainage at a lesser frequency. They usually maintain moderate to low physical activity which they described as walking, weight training, swimming or biking.

Research question #2

What is the family-type profile of young adults with cystic fibrosis and healthy young adults and is there a difference between them?

The use of the FACES III instrument provided the family-of-origin type. Subjects in each group were asked to describe their family of origin (their parents, siblings, or other) as it was for them growing up, termed FACES-Real. Then they were also asked to describe how they would have liked their family of origin to be, termed FACES-Ideal. The instruments provided summated scores for each subscale of cohesion and adaptability. Means for the total sample (N=297) for each subscale are compared to Olson's obtained means, in Table 11.
TABLE 11 - FACES III- Means on Cohesion & Adaptability Subscales

<table>
<thead>
<tr>
<th></th>
<th>Kimchi (1992)</th>
<th>Olson et al()</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N=297)</td>
<td>(N=2453)</td>
</tr>
<tr>
<td></td>
<td>Means</td>
<td>Means</td>
</tr>
<tr>
<td>Cohesion-Real</td>
<td>34.59</td>
<td>39.8</td>
</tr>
<tr>
<td>Cohesion-Ideal</td>
<td>40.30</td>
<td>39.8</td>
</tr>
<tr>
<td>Adaptability-Real</td>
<td>23.34</td>
<td>24.1</td>
</tr>
<tr>
<td>Adaptability-Ideal</td>
<td>30.35</td>
<td>24.1</td>
</tr>
</tbody>
</table>

Each subject’s score was then plotted in the appropriate square of the 16 family types (Figure 6). Frequency and percentages of family types by groups are provided in Tables 12 and 13. In terms of adaptability, more of the individuals in the healthy group were raised in chaotic families (21.4%) or flexible families (28.6%). More of the individuals with CF seemed to have been raised in structured families (33.6%) or rigid families (27.3%). However, this difference was not statistically significant at the .05 level. The results of the ideal portion revealed that 70.1% of the healthy individuals would have liked to have more chaotic families and less structured, less flexible and less rigid. In the CF group 62.2% would have liked to be raised in a more chaotic family and 26.6% opted for a more flexible family. In terms of cohesion, 35% of the healthy group were raised in disengaged families or separate families. Less grew up in connected families (25.3%) and only 3.9% grew up in an
FIGURE 6. CIRCUMPLEX MODEL: FAMILY TYPES OF TOTAL SAMPLE

- Healthy group
- CF group
### TABLE 12. FACES III - ADAPTABILITY SUBSCALE

<table>
<thead>
<tr>
<th></th>
<th>Healthy Group</th>
<th></th>
<th>CF Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%)</td>
<td>Frequency (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Real (N = 154)</td>
<td>Ideal (N = 154)</td>
<td>Real (N = 143)</td>
<td>Ideal (N = 143)</td>
</tr>
<tr>
<td>Chaotic</td>
<td>33 (21.4)</td>
<td>108 (70.1)</td>
<td>23 (16.0)</td>
<td>89 (62.2)</td>
</tr>
<tr>
<td>Flexible</td>
<td>44 (28.6)</td>
<td>30 (19.5)</td>
<td>32 (22/4)</td>
<td>38 (26.6)</td>
</tr>
<tr>
<td>Structured</td>
<td>41 (26.6)</td>
<td>11 (7.1)</td>
<td>48 (33.6)</td>
<td>11 (7.7)</td>
</tr>
<tr>
<td>Rigid</td>
<td>35 (22.7)</td>
<td>4 (2.6)</td>
<td>39 (27.3)</td>
<td>4 (2.8)</td>
</tr>
</tbody>
</table>

### TABLE 13. FACES III - COHESION SUBSCALE

<table>
<thead>
<tr>
<th></th>
<th>Healthy Group</th>
<th></th>
<th>CF Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%)</td>
<td>Frequency (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Real (N = 154)</td>
<td>Ideal (N = 154)</td>
<td>Real (N = 143)</td>
<td>Ideal (N = 143)</td>
</tr>
<tr>
<td>Disengaged</td>
<td>54 (35.0)</td>
<td>16 (10.4)</td>
<td>64 (44.7)</td>
<td>23 (16.0)</td>
</tr>
<tr>
<td>Separated</td>
<td>54 (35.0)</td>
<td>46 (29.9)</td>
<td>42 (29.4)</td>
<td>39 (27.3)</td>
</tr>
<tr>
<td>Connected</td>
<td>39 (25.3)</td>
<td>64 (41.6)</td>
<td>25 (17.5)</td>
<td>42 (29.4)</td>
</tr>
<tr>
<td>Enmeshed</td>
<td>6 (3.9)</td>
<td>28 (18.2)</td>
<td>11 (7.7)</td>
<td>38 (26.6)</td>
</tr>
</tbody>
</table>
enmeshed family. Higher numbers of individuals with CF were raised in disengaged families (44.7%) and separate families (29.4%), but less in connected (17.5%) and enmeshed (7.7%) families. The healthy individuals ideal family was a connected (41.6%) family, and they chose disengaged, separate, or enmeshed families less often. More of the individuals in CF group indicated that they would have liked to have been raised in a connected (29.4%) family, and 26.6% would have liked to have a more enmeshed family. The CF group would have liked to have much less disengaged family (16.0%) or a separate family (27.3%). These differences between the groups, using Pearson r correlations, were not significantly different at the 0.05 level.

In order to summarize the data, they were grouped into three categories of family types: Balanced, midrange, and extreme. Thirty-five percent of the healthy individuals and 25.1% of the individuals with CF were raised in balanced families, about 50% in each group were raised in midrange families, and approximately 20% were raised in extreme families. The differences between the groups shown in figure 7 were not statistically significant ($X^2=3.73, p=0.15$). More of the individuals in the CF group liked to have been raised in an extreme families and less in midrange families, and more subjects in the healthy group liked to have been raised in midrange families and less in balanced families.
FIGURE 7. FAMILY TYPES

- EXTREME
- MIDRANGE
- BALANCED
Research question #3

Is there a difference between health locus of control characteristics of young adults with cystic fibrosis and healthy young adults?

The two groups were compared on each subscale of the health locus of control (HLOC) instrument and on their highest score among the three subscales, which was designated as their type of control. With the internal HLOC and chance HLOC, no significant differences were found (Table 14). The difference between the two groups on the powerful other subscale was significant at the 0.05 level.

<table>
<thead>
<tr>
<th>TABLE 14 - Health Locus of Control (HLOC) Subscales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy group</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td><strong>HLOC-internal</strong></td>
</tr>
<tr>
<td>N</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>S.D.</td>
</tr>
<tr>
<td>t=</td>
</tr>
<tr>
<td>p=</td>
</tr>
<tr>
<td><strong>HLOC-chance</strong></td>
</tr>
<tr>
<td>N</td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>S.D.</td>
</tr>
<tr>
<td>t=</td>
</tr>
<tr>
<td>p=</td>
</tr>
</tbody>
</table>
Health locus of control characteristics were also tested within each group, healthy and CF, on the variable of sex. There were no differences in the CF group between males and females. In the healthy group there was a statistically significant difference between males and females on the variable of HLOC-powerful others ($t=2.54$, $p=0.01$) with a mean of 14.52 (S.D. = 4.09) for males, and a mean of 16.83 and (S.D. = 5.30) for females.

<table>
<thead>
<tr>
<th></th>
<th>Kimchi (1992) CF(N=143)</th>
<th>Healthy Students (N=154)</th>
<th>Wallston, et al. ( ) Chronic Patients (N=609)</th>
<th>College Students (N=749)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHLC</td>
<td>26.62</td>
<td>25.20</td>
<td>25.78</td>
<td>26.68</td>
</tr>
<tr>
<td>CHLC</td>
<td>17.58</td>
<td>15.82</td>
<td>17.64</td>
<td>16.72</td>
</tr>
<tr>
<td>PHLC</td>
<td>19.74</td>
<td>14.98</td>
<td>22.54</td>
<td>17.87</td>
</tr>
</tbody>
</table>
The highest score of the health locus of control on one of the three subscales was designated as the person's HLOC. A chi square analysis was done to detect differences between the healthy group and the CF group. The difference between the two groups was not statistically significant at the 0.05 level (Table 16).

**TABLE 16 - Health Locus of Control Distribution by Subscale**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Healthy group N=152</th>
<th>CF group N=142</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency (%)</td>
<td></td>
<td></td>
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\[X^2=6.55\]
\[p=0.08\]

Research question #4

Do family type, health locus of control, demographic variables, or severity of illness correlate with health maintenance behaviors of young adults with cystic fibrosis? Correlation analyses were performed with the following variables: family type, health locus of control (HLOC),
### TABLE 17. VARIABLE CORRELATION MATRIX - HEALTHY GROUP

<table>
<thead>
<tr>
<th>Variable</th>
<th>Cannt</th>
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<th>HLOC Chance</th>
<th>HLOC Powerful Others</th>
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* Significance of P < 0.05
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<th>HLOC Powerful Others</th>
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* Significance of $P < 0.05$
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* Significance of P <0.05
TABLE 18. (Continued)

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* Significance of P < 0.05
demographics, severity of illness, and health maintenance behaviors. Variability between subjects and within subjects was tested by analysis of variance. Tables 17 and 18 provide correlation matrices.

### Healthy group

A positive correlation was found between place of residence and HLOC powerful others ($r=0.20$, $p=0.02$). The larger the city, the higher the score on the HLOC other. A negative correlation was found between counseling and HLOC other ($r=-0.22$, $p=0.01$). The more counseling received, the lower the score on the HLOC powerful others subscale. The two other correlations between hours of work per week and cohesion on the FACES-real scale, and counseling and cohesion score of the FACES-real scale, although statistically significant, were not meaningful.

### CF group

**Physical Condition**

Physical condition was positively correlated to health maintenance behaviors ($r=0.26$, $p=0.01$). The worse the physical condition, the more health maintenance behavior one performed. Physical condition was also tested with the actual values of the FEV1 percent predicted and FVC percent predicted (Table 19). FEV1 was negatively correlated to health maintenance behavior ($r=-0.36$, $p=0.01$) and so was FVC ($r=-25$, $p=0.01$). The lower the FEV1 and FVC values (worse
condition) the higher the number of health maintenance behaviors. Physical condition was also correlated to Cantril’s Ladder which is a measure of subjects’ perception of their health at time of questionnaire completion. The score on the Cantril’s Ladder was negatively correlated to physical condition ($r=-0.25$, $p=0.01$). The higher (worse) the condition, the lower the score on Cantril’s Ladder. FEV1 and FVC were also correlated to Cantril’s Ladder (Table 19): FEV1 ($r=0.28$, $p=0.01$), FVC ($r=0.31$, $p=0.01$). The correlations were positive and indicated that as FEV1 and FVC decrease (worse condition), the score on the Cantril’s Ladder decreases as well.

Health locus of control -powerful others was also correlated to condition ($r=0.20$, $p=0.02$). It was positively correlated and indicated that the higher the physical condition (worse), the higher the score on the HLOC powerful others. FEV1 and FVC were negatively correlated to HLOC powerful others (Table 19): FEV1 ($r=-0.17$, $p=0.04$), FVC ($r=-0.20$, $p=0.01$). This correlation means that as FEV1 and FVC decreases (worse), the score on the HLOC powerful others increases. The only other variable that FEV1 and FVC were correlated with was age. FEV1 was negatively correlated with age ($r=-0.21$, $p=0.01$), and FVC was not significantly correlated ($r=-0.08$, $p=0.31$). The negative correlation indicated that FEV1 decreases as the person with CF gets older.
TABLE 19. VARIABLE CORRELATION MATRIX - CF GROUP

<table>
<thead>
<tr>
<th></th>
<th>Behavior Score</th>
<th>Sports Score</th>
<th>Age</th>
<th>CANTRIL</th>
<th>HLOCINTR</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEV&lt;sub&gt;1&lt;/sub&gt;</td>
<td>-0.36</td>
<td>0.05</td>
<td>-0.21</td>
<td>0.28</td>
<td>-0.17</td>
</tr>
<tr>
<td>P</td>
<td>0.01*</td>
<td>0.53</td>
<td>0.01*</td>
<td>0.01*</td>
<td>0.04*</td>
</tr>
<tr>
<td>N</td>
<td>(143)</td>
<td>(133)</td>
<td>(143)</td>
<td>(142)</td>
<td>(142)</td>
</tr>
<tr>
<td>FVC</td>
<td>-0.25</td>
<td>0.13</td>
<td>-0.08</td>
<td>0.31</td>
<td>-0.20</td>
</tr>
<tr>
<td>P</td>
<td>0.01*</td>
<td>0.14</td>
<td>0.32</td>
<td>0.01*</td>
<td>0.01*</td>
</tr>
<tr>
<td>N</td>
<td>(143)</td>
<td>(133)</td>
<td>(143)</td>
<td>(142)</td>
<td>(142)</td>
</tr>
</tbody>
</table>

* Significance of P < 0.05

FEV<sub>1</sub> = Forced expiratory volume at one second
FVC = Forced vital capacity

**Age**

Age was negatively correlated with the Cantril's Ladder ($r=-0.27$, $p=0.01$) and indicated that as a person with CF gets older, the score on the ladder decreases (worse health). Age was also negatively correlated with HLOC powerful others ($r=-0.17$, $p=0.04$) and showed that the older the individuals with CF, the lower their score on the HLOC powerful others. The correlation between age and the adaptability scale of FACES-Real was also negative ($r=-0.29$, $p=0.01$) and pointed out that the older the individuals with CF, the lower the score they marked on adaptability in their family of origin.
Familial Variables

The presence of children in their families of procreation was positively correlated to the Cantril's Ladder ($r=0.27$, $p=0.01$) and indicated that the presence of children was correlated to a higher score (better health) on the ladder. The variable of children also positively correlated to the cohesion scale on the FACES-Real ($r=0.18$, $p=0.03$), however, although statistically significant, this correlation is not meaningful.

Number of siblings with CF was positively correlated HLOC internal ($r=0.17$, $p=0.04$) which meant that the higher the number of siblings with CF (dead or alive) the higher their score on the internal subscale of the Health Locus of Control. Number of siblings with CF was also positively correlated to the cohesion subscale of FACES-Real ($r=0.17$, $p=0.04$) which indicated that the higher the number of siblings with CF, the higher their score on the cohesion scale of FACES-Real.

Income and Education

1990 income was positively correlated with HLOC chance ($r=0.19$, $p=0.03$) which meant that the higher the income the higher their score on the chance subscale on the Health Locus of Control.

The education variable was negatively correlated to HLOC powerful others ($r=-0.26$, $p=0.01$) which indicated that the more years of education one had, the lower his/her score on
the powerful others subscale of the HLOC instrument.

**Counseling**

Counseling (Table 20) was positively correlated with the Cantril's Ladder ($r=0.18$, $p=0.03$) which showed that individuals' attendance of counseling sessions was correlated with higher score (better health) on the ladder. People that used psychological/psychiatric counseling within the last year (Table 19) also scored higher on the adaptability subscale of FACES-Real ($r=0.16$, $p=0.04$) and on the cohesion subscale of FACES-Real ($r=0.19$, $p=0.02$).

**Hospital Days**

Number of hospitalization days were positively correlated with health maintenance behaviors ($r=0.28$, $p=0.01$), which indicated the the higher number of hospitalization days in the past year, the more health maintenance behaviors performed by individuals with CF.

**Other Correlations**

Hours of work per week were negatively correlated with the cohesion scale of FACES-Real ($r=-0.22$, $p=0.03$), and work conditions were positively correlated with the same subscale ($r=0.27$, $p=0.01$). However, although statistically significant, the correlation appears to be meaningless.

Sports score, did not significantly correlate with any variable (Table 20): with condition ($r=-0.06$, $p=0.47$), with


<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Healthy Individuals</td>
<td>Individuals with CF</td>
</tr>
<tr>
<td>Psychological/Psychiatric Counseling Last 12 Months</td>
<td>(N = 154)</td>
<td>(N = 142)</td>
</tr>
<tr>
<td>Yes</td>
<td>16 (10.4)</td>
<td>18 (12.7)</td>
</tr>
<tr>
<td>No</td>
<td>154 (89.6)</td>
<td>142 (87.3)</td>
</tr>
<tr>
<td>Hospitalization</td>
<td>(N = 154)</td>
<td>(N = 143)</td>
</tr>
<tr>
<td>Yes</td>
<td>16 (10.4)</td>
<td>73 (51)</td>
</tr>
<tr>
<td>No</td>
<td>138 (89.6)</td>
<td>70 (49)</td>
</tr>
<tr>
<td>Number of Hospitalization Days</td>
<td>(N = 154)</td>
<td>(N = 142)</td>
</tr>
<tr>
<td>0 Days</td>
<td>138 (89.6)</td>
<td>71 (50)</td>
</tr>
<tr>
<td>1-10 Days</td>
<td>15 (9.8)</td>
<td>27 (19)</td>
</tr>
<tr>
<td>11-20 Days</td>
<td>1 (0.6)</td>
<td>18 (12.6)</td>
</tr>
<tr>
<td>21-30 Days</td>
<td>0</td>
<td>16 (11.2)</td>
</tr>
<tr>
<td>31-40 Days</td>
<td>0</td>
<td>5 (3.6)</td>
</tr>
<tr>
<td>41-60 Days</td>
<td>0</td>
<td>5 (3.6)</td>
</tr>
<tr>
<td>$\bar{x}$</td>
<td>0.318</td>
<td>8.838</td>
</tr>
<tr>
<td>S.D.</td>
<td>1.347</td>
<td>12.947</td>
</tr>
</tbody>
</table>
FEV1 ($r=0.05$, $p=0.53$), with FVC ($r=0.13$, $p=0.14$), with behavior score ($r=0.09$, $p=0.30$), with HLOC internal ($r=-0.01$, $p=0.98$), with HLOC chance ($r=-0.11$, $p=0.19$), and with HLOC powerful others ($r=-0.10$, $p=0.25$).

The frequency of health maintenance behaviors are provided in table 21.

### TABLE 21 - Health Maintenance Behaviors

<table>
<thead>
<tr>
<th>CF group</th>
<th>Behavior Score</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None (0)</td>
<td>1 (0.7)</td>
<td></td>
</tr>
<tr>
<td>Low (1-19)</td>
<td>3 (2.0)</td>
<td></td>
</tr>
<tr>
<td>Moderate (20-38)</td>
<td>37 (25.9)</td>
<td></td>
</tr>
<tr>
<td>Good (39-57)</td>
<td>56 (39.2)</td>
<td></td>
</tr>
<tr>
<td>High (58-76)</td>
<td>46 (32.2)</td>
<td></td>
</tr>
</tbody>
</table>

Mean = 46.28  
S.D. = 15.5

Less than 3% of individuals with CF maintained a low behavior score. Majority (97%) of the sample maintained either a moderate, good, or high behavior score. Analysis of variance performed on behavior score and sports score with several other variables were not statistically significant (see Table 22 and Table 23).
### TABLE 22. SPORTS SCORE - CF GROUP
**Analysis of Variance**

<table>
<thead>
<tr>
<th>Variable</th>
<th>df (Between subjects, subjects within groups)</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Arrangements</td>
<td>129, 125</td>
<td>1.708</td>
<td>6.29</td>
</tr>
<tr>
<td>No. of Siblings with CF</td>
<td>131, 128</td>
<td>1.615</td>
<td>0.18</td>
</tr>
<tr>
<td>CF Knowledge</td>
<td>132, 129</td>
<td>0.170</td>
<td>0.92</td>
</tr>
<tr>
<td>FACES - Real</td>
<td>130, 128</td>
<td>0.356</td>
<td>0.70</td>
</tr>
<tr>
<td>FACES - Ideal</td>
<td>130, 128</td>
<td>1.334</td>
<td>0.27</td>
</tr>
</tbody>
</table>

### TABLE 23. HEALTH MAINTENANCE BEHAVIORS - CF GROUP
**Analysis of Variance**

<table>
<thead>
<tr>
<th>Variable</th>
<th>df (Between subjects, subjects within groups)</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Arrangements</td>
<td>139, 135</td>
<td>1.286</td>
<td>0.89</td>
</tr>
<tr>
<td>No. of Siblings with CF</td>
<td>141, 138</td>
<td>0.110</td>
<td>0.95</td>
</tr>
<tr>
<td>CF Knowledge</td>
<td>142, 139</td>
<td>0.129</td>
<td>0.94</td>
</tr>
<tr>
<td>FACES - Real</td>
<td>140, 138</td>
<td>1.156</td>
<td>0.36</td>
</tr>
<tr>
<td>FACES - Ideal</td>
<td>140, 138</td>
<td>0.255</td>
<td>0.78</td>
</tr>
</tbody>
</table>
Research question #5

Do family type and health locus of control variables predict health maintenance behaviors of young adults with cystic fibrosis?

The final data analysis procedure was intended to involve a stepwise logistic regression to assess the independent and interactive effects of the variables shown to be statistically significant on univariate analysis. However, only one factor, HLOC powerful others was shown to be significant on the univariate analysis; the results of the logistic regression were, of course, not significant. Thus, family type and health locus of control do not predict health mainenance behaviors of young adults with cystic fibrosis.

Early respondents and late respondents

Early respondents (N=112) and late respondents (N=31) were compared on several variables: age (t=0.342, p=0.89) health maintenance behavior score (t=1.17, p=0.67), educational status ($\chi^2=1.34, p=0.05$), and physical condition ($\chi^2=0.34, p=0.84$). No significant differences were found between the two groups, thus late respondents were concluded to be similar to early respondents.
Respondents and non-respondents

In a subsequent analysis, respondents were compared to non-respondents on the variables of age ($t=1.67$, $p=0.68$) and physical condition ($X^2=0.08$, $p=0.96$). Other variables for comparison were not available for the non-respondents group. Based on these results, it was concluded, that respondents and non-respondents were similar.
CHAPTER V

Discussion

The purpose of this study was to assess and test possible predicting variables that affect health maintenance behaviors of young adults with cystic fibrosis (CF). One hundred and forty three adults with CF, drawn from 10 CF centers, were compared to 153 healthy young students from a large Midwestern university. Statistical testing of the data revealed that the two groups were more alike than expected.

One of the main differences was living arrangements. About half of the healthy students lived with a roommate and only 24% lived with one or both parents, as compared to 40% of the individuals in the CF group who lived with one or both of parents. This difference might reflect the tendency of college students to move away from their parents and hometowns and live on or around campus, usually with a roommate. Another notable difference was that 63% of the adults with CF lived less than 50 miles from their parents as compared to 22% of the healthy group. This finding is consistent with the findings of Strauss and Wellisch (1981). This difference may be attributed to illness related needs of persons with CF and not just a reflection of student status of the healthy
group since 46% of the CF group were also students.

The two groups were also compared on education and work. The CF group had twice as many individuals with a two-year degree and more people in the CF group earned higher annual salaries. Having more two year degrees may reflect the sense of shortness of time to pursue longer educational programs, but also may be attributed to being compared to a group that is pursuing a four year degree. Higher annual salaries for the CF group may reflect their presence in the work force longer than the students still in college. Two thirds of the healthy group and one third of the CF group had no occupation. There were no remarkable differences between the groups on occupation except that students worked more in child care and individuals with CF did more maintenance work. In summary, most of the differences in demographic characteristics between the two groups seem to be attributed to normal differences between students and non students. The results of this study are consistent with the findings by Cowen, et al (1984) who found young adults with CF to be independent with the majority living on their own, holding variety of jobs or attending college.

Examination of the family-of-origin type revealed that both groups were raised in either disengaged (more individuals in the CF group) or separate families. Disengaged families have very low levels of cohesion and members tend to “do their own thing” with limited attachment or commitment to their family. This type of family is seen as
problematic. Separate families have low to moderate levels of cohesion which enable individual to balance independence and connectedness, and is seen as a balanced family with optimal family functioning. Most individuals from both groups chose a connected family as their ideal family. The relationships in a connected family are characterized by emotional closeness and loyalty to the relationship. Time together is more important then time apart, there are separate and shared friends, and there are shared interests. This type of family has moderate to high levels of cohesion.

Individuals in the healthy group were evenly divided between all family types for the adaptation subscale. A higher percentage of individuals with CF were raised in structured families or rigid families. A structured family is able to balance change and stability, whereas, a rigid family has a very low level of change and high level of stability. For their ideal family, the majority of each group chose a chaotic family type which has high levels of change and little stability. It is interesting that contrary to the investigator's contention that many individuals with external or chance health locus of control orientation will be raised in rigidly enmeshed and chaotically enmeshed families, none of the subjects were raised in a rigidly enmeshed family, and only about 15% in both groups were raised in chaotically enmeshed families. It is also of interest that although many of the subjects grew up in balanced families, most of them would have liked a more
chaotic family which is characterized by erratic leadership, ineffective discipline, impulsive decisions, endless negotiations, lack of role clarity, role reversal, and frequent role change. In summary, both groups would liked to have been raised in a family that was less structured with less rules but with more emotional closeness and more shared interests and friends.

The majority of young adults with CF maintained either a low or moderate level of physical activity and performed several health maintenance behaviors: took enzymes and vitamins, used aerosols, and about half of the sample performed postural drainage. There are no other surveys on adults with CF in the literature, thus this level and type of activity and can not be compared to any other studies.

Health locus of control (HLOC) characteristics between the two groups differed only on the powerful others subscales. This difference seems logical since individuals cared for from childhood by health professionals will attribute some control over their health to these care takers. However, both of the groups did not differ on internal health locus of control or chance health locus of control. This finding may indicate that families of healthy children use similar child-rearing practices as do families of children with CF. Both groups of families can be either overprotective (allow little independence) or not protective (allow much independence) which may explain the non significant difference in health locus of control orientation
between the healthy group and the CF group. In reference to Pender’s (1987) model, the component of perceived control as measured by the Multidimensional Health Locus of Control Scale, did not seem to have any predictive validity in regard to health maintenance behaviors of young adults with CF.

Pender (1987) also notes that perception of control may be mediated by ethnic background, socioeconomic status and patterns of child rearing, but have not yet been studied. In this study, religious affiliation, income, and child-rearing practices (measured indirectly by type of family-of-origin), were tested; none of these variables were shown to serve as modifying factors in determining to carry out health maintenance behaviors. Age was shown to be a significant modifying variable: the older the individuals with CF (the worse their condition), the more health maintenance behaviors they performed.

Two perceived barriers to actions were tested: distance from CF clinic and lack of health insurance. Both variables were not statistically significant in affecting decision to carry out health maintenance behaviors. One cue for action, perception of fatigue, was mentioned by several patients as a reason for not carrying out any health maintenance activities, but it was not tested.

Few significant correlations were found within the healthy group. One such positive correlation was between place of residence and HLOC powerful others. The larger the place of residence, the higher the students scored on HLOC
powerful others. It may be attributed to the fact that in a large city and a large university, and in the absence of family members, students may find themselves in situations in which other people have more control over their health than they do. In relation to counseling, those that attended counseling sessions, scored lower on the HLOC powerful others. This seems to indicate that counseling was probably helping, and people that attended these sessions seemed to have a decreased perspective of dependency on others. They felt in better control of their health.

Several of the statistically significant correlations in the CF group related to physical condition. Health maintenance behaviors increased when physical condition deteriorated, which is consistent with the Suchman’s (1967) findings. The sicker one gets, the more measures he/she is going to take to get better. This finding seems to correspond to the perceived threat-perceived seriousness component in Pender’s (1987) model. When deterioration of physical condition occurred, perceived seriousness and threat were realized, which in turn lead to action of performing more health maintenance activities, probably motivated by perceived benefits of improvement of health status (short term goal) and longevity (long term goal). This was also apparent in the positive correlation between number of hospital days and health maintenance behaviors, in which hospitalization increased one’s awareness to seriousness and threat to survival.
The score on the Cantril ladder also decreased as the physical condition worsened. The sicker one feels the lower he/she is going to mark a scale which asks about how healthy you feel in relationship to other people you know. Dependency on others for health care, as manifested in the health locus of control—powerful others, was also correlated to physical condition. As one's physical condition deteriorates he/she is more likely to score higher on the HLOC powerful others which indicates the individual's perception that other people, usually health professionals, have more control over his health than he/she does. FEV1, the more sensitive indicator of pulmonary function, was negatively correlated with age. As a person with CF gets older, his FEV1 decreases (gets worse). However, FVC was not significantly correlated with age. FEV1 was chosen as the indicator of physical condition, and these results indicated that indeed FEV1 is a more sensitive indicator and should have been chosen. Age was also negatively correlated with the Cantril ladder, which again indicate that as a person with CF gets older, his health deteriorates, which in turn will reflect the marking on the ladder. In relation to HLOC powerful others, the older the person with CF, the lower his/her score on this subscale. This could mean that the older one gets, the more confidence one gains in his ability to deal with his/her condition and less control is attributed to other people. Correlations between age and adaptability imply that the older the individuals with CF, the lower their
score on adaptability in their family of origin. They recalled less change and more stability in their family of origin.

Presence of children seemed to make adults with CF feel better about their health as made evident by the higher markings on the Cantril ladder. Individuals that had siblings with CF, dead or alive, seemed to score higher on the internal locus of control subscale. Number of siblings with CF was positively correlated to higher scores on cohesion of family of origin. Maybe growing up with other siblings with CF helped each person realize that they are responsible for their own health, but also forced family members to become close and helpful to one another.

Education was negatively correlated to HLOC powerful others, which seem to indicate that the more educated a person, the less likely he/she is going to attribute control over his/her health to other people.

Counseling seemed to have helped individuals with CF to feel healthier as was reflected in their higher scores on the Cantril ladder. Counseling also was correlated to higher scores of adaptability and cohesion in their family of origin. This might indicate that they tended to see their families in a more positive way.

Number of hospitalization days during the past year was correlated with health maintenance behaviors. It may indicate that hospitalization brings one's vulnerability to the conscious, which in turn motivates people to take better
care of themselves, at least for a while.

Conclusions

The results of this study do not provide any support to a predictive model of health maintenance behaviors of young adults with cystic fibrosis based on health locus of control or type of family of origin. Many of the findings show very little difference between young adults with CF and healthy young adults. Further, the differences that do exist seem to logically stem from the fact that the young adults with CF have a chronic condition. In general, young adults with CF were very well adjusted to their chronic condition and saw themselves only slightly less well in terms of their physical condition than compared to healthy young adults. More of them, compared to healthy young adults, attributed control over their health to powerful others, possibly health professionals.

Type of family of origin and health locus of control do not differentiate between healthy young adults and young adults with cystic fibrosis. Furthermore, type of family of origin and health locus of control do not affect health maintenance behaviors. Thus, being raised in a certain type of family that encourages or discourages independence does not necessarily guarantee a certain health locus of control orientation. Most individuals in the CF group were internal
in their health locus of control belief even though they were raised in 16 different types of families.

The results of this study seem to indicate that although the patients had different degrees of illness severity overall, they felt just a little sicker than the healthy young adults. This small, but significant difference, may be attributed to the fact that most of them have been diagnosed since childhood and at the time they reached young adulthood they had adjusted to their condition and now do not feel different than healthy young adults. They are adjusted to a certain physical baseline that may be different for a healthy person but might be the definition of personal "normal" for the CF young adults.

Health maintenance behaviors were shown to be correlated with physical condition. This finding parallels the behavior of healthy adults when it comes to health prevention behaviors. Healthy adults often do not take adequate preventive actions until there is a perceived threat of some illness; then preventive actions may be taken. It may be that the needs of young adults with CF are similar to those of healthy young adults; health professionals may need to begin looking at these commonalities rather than looking for differences.
Recommendations for Future Research

The recommendations based on the results of this study include the areas of research and clinical practice. In this study health maintenance behaviors of young adults with CF were studied in the context of a family framework—health locus of control, which is believed to be developed during adolescence and thus it is affected by the family system, and one’s own family of origin. Future studies should attempt to explore different constructs that are not related to family functioning and dependence or independence of children with chronic illnesses. An example for such a construct could be perceived seriousness or perceived threat of an illness as a motivator for health maintenance behavior.

If the study is to be replicated, it should probably be conducted in geographical areas other than the Midwest, since treatment of patients with CF might differ between the two coasts and the Midwest.

Variables that were measured in this study should be measured more sensitively. Several patients did not engage in any physical activity, however, their jobs or their lifestyle demanded certain level of energy exertion that left them too tired to carry out other activities. Daily estimates of physical activity will provide a much better understanding of their activity level.

Family of origin was only indirectly measured in this study and it depended on recall. It is recommended that a
prospective study be conducted of families of children with CF that will include children with various levels of dependence and independence as it relates to their chronic condition. The effects of type of family of origin as it relates to the health maintenance behaviors of chronically ill children, may then become evident.

Young adults that visited either a psychologist or a psychiatrist in the past 12 months were shown to feel better about their health as indicated by their responses on the Cantril' ladder. In many CF centers young adults are only counseled when problems arise. Counseling every adult patient might be a strategy to explore as a mechanism for promoting effective coping with the chronic condition.

Currently, many health professionals advise parents to encourage as much independence of care in children and adolescents with chronic illness and to discourage dependency. The results of this study do not support the notion that certain type of families help develop a certain health locus of control, and should be further explored.

Scientific strides have been made in the last decade in the biological/physiological areas of CF, however, a discrepancy exists between these state of the art developments and the existing knowledge on young adults with CF. The studies that have been conducted examined psychological and demographic variables, but none looked at the interaction between these variables and health maintenance behaviors. Studies that explore health
maintenance behaviors of young adults with a chronic illness are recommended in order to make health professionals more familiar with issues relevant to the adult with CF.
LIST OF REFERENCES


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Appendix A

Questionnaire - Healthy Group
HEALTH BEHAVIORS OF YOUNG ADULTS
Dear prospective participant,

My name is Judy Kimchi and I am a doctoral student at the Ohio State University, College of Nursing. I am conducting a study under the direction of Dr. Joanne Stevenson. The purpose of this study is to compare the life style of healthy young adults with young adults who have cystic fibrosis. The results of this research should help in planning better health care programs for younger adults with cystic fibrosis.

I am interested in your views on health-related issues, your own health, and your family of origin (meaning your parents & siblings or other), and would like to invite you to participate. Your participation will be greatly appreciated. However, it is voluntary, and not participating will have NO bearing on your grade in this course.

The attached questionnaires should take no longer than 15-20 minutes to complete. The questions are easy to answer and there are no right or wrong answers. The right answer is only what you think is right. All the information you provide will remain confidential and will be reported only as group data.

If you decide to participate, please read and sign the following statement: I have read the above information and understand it. I hereby agree to participate in the study.

___________________________  ____________________________
Date                    Your signature

If you decide not to participate, please kindly indicate your reason __________________________________________________________

then, return the packet of materials to the researcher.

Sincerely,

Judy Kimchi RN, MS

THANK YOU 😊
This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to CIRCLE the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

1. If I get sick, it is my own behavior which determines how soon I will get well again.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

2. No matter what I do, if I am going to get sick, I will get sick.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

3. Having regular contact with my physician is the best way for me to avoid illness.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

4. Most things that affect my health happen to me by accident.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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5. Whenever I don't feel well, I should consult a medically trained professional.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

6. I am in control of my health.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

7. My family has a lot to do with my becoming sick or staying healthy.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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8. When I get sick, I am to blame.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

9. Luck plays a big part in determining how soon I will recover from an illness.
   | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
   | 1 | 2 | 3 | 4 | 5 | 6 |

10. Health professionals control my health.
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11. My good health is largely a matter of good fortune.
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12. The main thing which affects my health is what I myself do.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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13. If I take care of myself, I can avoid illness.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
    | 1 | 2 | 3 | 4 | 5 | 6 |

15. No matter what I do, I'm likely to get sick.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
    | 1 | 2 | 3 | 4 | 5 | 6 |

16. If it's meant to be, I will stay healthy.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
    | 1 | 2 | 3 | 4 | 5 | 6 |

17. If I take the right actions, I can stay healthy.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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18. Regarding my health, I can only do what my doctor tells me to do.
    | Strongly Disagree | Moderately Disagree | Slightly Disagree | Slightly Agree | Moderately Agree | Strongly Agree |
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**FACES III**

David H. Olson, Joyce Portner, and Yoav Lavee

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*WRITE IN THE NUMBER THAT BEST DESCRIBES HOW YOUR FAMILY OF ORIGIN (your parents, siblings, or other) WAS AS YOU WERE GROWING UP:*

© D.H. Olson, 1985
FACES III: Ideal Version

David H. Olson, Joyce Portner, and Yoav Lavee

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*WRITE IN THE NUMBER THAT BEST DESCRIBES HOW YOU WOULD HAVE LIKED YOUR FAMILY OF ORIGIN (your parents & siblings, or other) TO BE:

21. Family members would ask each other for help.
22. In solving problems, the children's suggestions would be followed.
23. We would approve of each other's friends.
24. The children would have a say in their discipline.
25. We would like to do things with just our immediate family.
26. Different persons would act as leaders in our family.
27. Family members would feel closer to each other than to people outside the family.
28. Our family would change its way of handling tasks.
29. Family members would like to spend free time with each other.
30. Parent(s) and children would discuss punishment together.
31. Family members would feel very close to each other.
32. Children would make the decisions in our family.
33. When our family got together, everybody would be present.
34. Rules would change in our family.
35. We could easily think of things to do together as a family.
36. We would shift household responsibilities from person to person.
37. Family members would consult each other on their decisions.
38. We would know who the leader(s) was in our family.
39. Family togetherness would be very important.
40. We could tell who does which household chores.
Below is a picture of a ladder with each rung numbered from zero (0) on the bottom rung to nine (9) on the top rung. Imagine that the top of the ladder (9) represents the best possible health status for you and the bottom (0) represents the worse possible health status for you. In comparison to other healthy people you know where would you place yourself at the present time?

Please put a check (√) on the line beside the rung which represents your present health status. There is no right or wrong answer, only what best applies to you.

BACKGROUND INFORMATION ON PARTICIPANTS

The demographic information will be used for statistical analysis. All the information is confidential and will only be reported as group data.

1. What is your sex? (Please circle one)
   1. MALE
   2. FEMALE

2. How old were you on your last birthday?
   1. 18
   2. 19
   3. 20
   4. 21
   5. 22
   6. 23
   7. 24
   8. 25
   9. 26
   10. 27
   11. 28
   12. OTHER (please write in)

3. What is your marital status? (Please circle one)
   1. NEVER MARRIED
   2. MARRIED
   3. DIVORCED
   4. WIDOWED
   5. SEPARATED
   6. COHABITATION

4. Do you have any children?
   1. YES
   2. NO

5. If you do have child/ren were they:
   1. NATURALLY CONCEIVED
   2. ADOPTED
   3. CONCEIVED BY ARTIFICIAL INSEMINATION
6. Where do you live?  
(Please circle one)

1. METROPOLIS (over 100,000)
2. CITY (50,000-100,000)
3. SMALL CITY (10,000-50,000)
4. TOWN (2,500-10,000)
5. SMALL TOWN (under 2,500)
6. RURAL BUT NOT A FARM
7. ON A FARM

7. With whom do you live? (Please circle one)

1. BY YOURSELF
2. WITH YOUR PARENTS
3. WITH YOUR SPOUSE
4. WITH A ROOMMATE
5. OTHER _________ (Please specify)

8. If you do not live with your parents, how far is your parents' residence from yours?

1. LESS THAN 50 MILES
2. MORE THAN 50 MILES
3. MORE THAN 100 MILES
4. MORE THAN 200 MILES
5. OTHER __________________ (please specify)

9. What is your religion, if any?  
(Please circle one)

1. CHRISTIAN
2. CATHOLIC
3. JEWISH
4. MUSLIM
5. BUDDHIST
6. NONE
7. OTHER ________________ (please specify)

10. What is your occupation/profession?  
(Please write in)  

______________________________
11. Are you currently employed?
   (Please circle one)
   1. Yes
   2. No

12. How long have you worked at your current job?
   1. LESS THAN 1 YEAR
   2. LESS THAN 2 YEARS
   3. MORE THAN 2 YEARS
   4. MORE THAN 3 YEARS
   5. MORE THAN 4 YEARS
   6. MORE THAN 5 YEARS
   7. OTHER ______________ (Please specify)

13. How many hours per week do you work?
    (Please circle one)
    1. LESS THAN 10 HOURS
    2. 10-20 HOURS
    3. 20-30 HOURS
    4. 30-40 HOURS
    5. MORE THAN 40 HOURS
    6. MY WEEKLY HOURS VARY
    7. I WORK ONLY DURING THE SUMMER

14. Does your job require hard physical work?
    (Please circle one)
    1. YES
    2. NO

15. Which of these broad categories describes your total income
    before taxes in 1990?
    1. LESS THAN $10,000
    2. $10,000 TO $14,999
    3. $15,000 TO $19,999
    4. $20,000 TO $24,999
    5. $25,000 TO $29,999
    6. $30,000 TO $39,000
    7. $40,000 TO $49,999
    8. $50,000 TO $64,999
    9. $65,000 OR MORE
16. What is your highest educational degree?

1. 9TH GRADE
2. 10TH GRADE
3. HIGH SCHOOL DIPLOMA OR EQUIVALENCY
4. ASSOCIATE, TWO YEAR, JUNIOR COLLEGE DEGREE
5. BACHELOR'S DEGREE
6. MASTER'S DEGREE
7. DOCTORATE
8. PROFESSIONAL (MD, DDS, etc.)
9. OTHER_________________________ (please specify)

17. Which of the following indicates your current educational status?

1. FULL TIME STUDENT
2. PART TIME STUDENT
3. I AM NOT A STUDENT
4. OTHER ________________________ (Please specify)

18. Your health care costs are covered by:
(Please circle one)

1. A PRIVATE INSURANCE COMPANY
2. BY A FEDERAL HEALTH PROGRAM
3. BY BOTH A PRIVATE INSURANCE COMPANY AND BY A FEDERAL HEALTH PROGRAM
4. YOU HAVE NO HEALTH CARE INSURANCE
5. OTHER ________________________ (Please specify)

19. If you have health care insurance, the policy is:
(Please circle one)

1. YOUR OWN
2. YOUR PARENTS’ POLICY
3. YOUR SPOUSE'S POLICY
4. YOU HAVE NO HEALTH CARE INSURANCE
5. OTHER_________________________ (Please specify)
20. Have you sought any psychological/psychiatric counseling during the past twelve months?
   1. YES
   2. NO

21. Who is the most helpful person in helping you solve everyday problems of living?
   1. MOTHER
   2. FATHER
   3. BROTHER
   4. SISTER
   5. PEER (boyfriend; girlfriend; spouse; roommate, etc.)
   6. CLERGYMAN
   7. PHYSICIAN
   8. NURSE
   9. SOCIAL WORKER
  10. SCHOOL COUNSELOR
  11. FRIEND/S
  12. PSYCHOTHERAPIST
  13. OTHER

22. Have you been hospitalized in the past 12 months?
   1. YES
   2. NO

23. If yes, how many days did you stay at the hospital?

24. Do you have a chronic illness?
   1. YES
   2. NO

25. If you do have a chronic illness, please write it in _________________________________ (Optional)
26. Do you smoke? (Please circle one)
   1. YES
   2. NO

27. Do you live with someone who smokes? (Please circle one)
   1. YES
   2. NO

28. Does he/she smoke in your presence? (Please circle one)
   1. YES
   2. NO

THANK YOU 😊
HEALTH BEHAVIORS OF YOUNG ADULTS WITH CYSTIC FIBROSIS

Columbus Children's Hospital
Cystic Fibrosis Center
700 Children's Drive
Columbus, Ohio 43205
Dear Participant:

The purpose of this questionnaire is to learn about your views on health-related issues, your own health, and your family of origin.

Your responses are very important, so please answer each question as accurately as possible.

Thank you!
This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6).

- strongly disagree (1)
- moderately disagree (2)
- slightly disagree (3)
- slightly agree (4)
- moderately agree (5)
- strongly agree (6)

For each item we would like you to CIRCLE the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, the higher will be the number you circle. The more strongly you disagree with a statement, the lower will be the number you circle. Please make sure that you answer every item and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.
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</tr>
<tr>
<td>17</td>
<td>Family members consult other family members on their decisions.</td>
<td></td>
<td></td>
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<tr>
<td>18</td>
<td>It is hard to identify the leader(s) in our family.</td>
<td></td>
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<tr>
<td>19</td>
<td>Family togetherness is very important.</td>
<td></td>
<td></td>
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<tr>
<td>20</td>
<td>It is hard to tell who does which household chores.</td>
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</tbody>
</table>

* Write in the number that best describes how you would have liked your family of origin (your parents & siblings, or others) to be:

<table>
<thead>
<tr>
<th></th>
<th>ALMOST NEVER</th>
<th>ONCE IN A WHILE</th>
<th>SOMETIMES</th>
<th>FREQUENTLY</th>
<th>ALMOST ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>21</td>
<td>Family members would ask each other for help.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>22</td>
<td>In solving problems, the children's suggestions would be followed.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>23</td>
<td>We would approve of each other's friends.</td>
<td></td>
<td></td>
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<tr>
<td>24</td>
<td>The children would have a say in their discipline.</td>
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<td></td>
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<tr>
<td>25</td>
<td>We would like to do things with just our immediate family.</td>
<td></td>
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<tr>
<td>26</td>
<td>Different persons would act as leaders in our family.</td>
<td></td>
<td></td>
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<tr>
<td>27</td>
<td>Family members would feel closer to each other than to people outside the family.</td>
<td></td>
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<tr>
<td>28</td>
<td>Our family would change its way of handling tasks.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Family members would feel very close to each other.</td>
<td></td>
<td></td>
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<tr>
<td>30</td>
<td>Parent(s) and children would discuss punishment together.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>31</td>
<td>Family members would feel very close to each other.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Children would make the decisions in our family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>When our family gets together, everybody would be present.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>Rules would change in our family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>We could easily think of things to do together as a family.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>36</td>
<td>We would shift household responsibilities from person to person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>Family members would consult each other on their decisions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>We would know who the leader(s) was in our family.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39</td>
<td>Family togetherness would be very important.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>We could tell who does which household chores.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following question is about your health.

Below is a picture of a ladder with each rung numbered from zero (0) on the bottom rung to nine (9) on the top rung. Imagine that the top of the ladder (9) represents the best possible health status for you and the bottom (0) represents the worst possible health status for you. In comparison to other healthy people you know where would you place yourself at the present time?

Please put a check (✓) on the line beside the rung which represents your present health status. There is no right or wrong answer, only what best applies to you.

The following is a list of physical activities, please write in how many times EACH WEEK you do each of the following:

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>YES</th>
<th>NO</th>
<th>HOW OFTEN</th>
<th>DOCTOR'S ORDERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aerobics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biking</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Hiking</td>
<td></td>
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<tr>
<td>Hunting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jogging</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skiing</td>
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<tr>
<td>Swimming</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight Training</td>
<td></td>
<td></td>
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<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

1  
Please indicate how often you engage in the following behaviors. This information is for research purposes only and will not be shared with the clinic staff. Data will only be reported as group data.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>How Often</th>
<th>Doctor's Orders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Times Per Day</td>
<td>Times Per Week</td>
</tr>
<tr>
<td>Aerosols (any kind)</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Postural Drainage</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Night time oxygen</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Take Enzymes</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Oral nutritional supplements (Ensure; milkshakes)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home IV TPN</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Tube feedings</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Take vitamins</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Oral bronchodilators</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Antibiotics</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Monitor glucose</td>
<td></td>
<td>Yes  No</td>
</tr>
<tr>
<td>Take hypoglycemics (insulin; Glimtide)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Many patients do not always comply with their doctor's instructions for a variety of reasons. If you do not follow some of the doctor's orders, please share some of your reasons.

---

6. For the following conditions please put a check mark beside each one of the following that you have had during the past two years:

1. HEMOPTYSIS (Coughing up blood)  
2. PNEUMOTHORAX (Collapsed lung)  
3. HEART STRAIN DUE TO LUNG CONDITION  
4. DIABETES MELLITUS (Sugar)  
5. LIVER ABNORMALITY  
6. INTESTINAL OBSTRUCTION  
7. OTHER (please specify)

---

7. Have you ever had any of the following surgeries?

1. TUBAL LIGATION  
2. ABDOMINAL SURGERY  
3. PULMONARY SURGERY  
4. SINUS SURGERY

---

3. How many times have you visited the CF clinic during the past year? (estimate)  
4. How many visits were you expected to make during the past year?  
5. How many times have you visited a physician (not in the CF clinic) in matters related to your CF condition during the past year? (estimate)
What is your sex? (Please circle one)
1. MALE
2. FEMALE

How old were you on your last birthday? (Please circle one)
1. 18 7 24
2. 19 8 25
3. 20 9 26
4. 21 10 27
5. 22 11 28
6. 23 12 OTHER (please write in)

What is your marital status? (Please circle one)
1. NEVER MARRIED
2. MARRIED
3. DIVORCED
4. WIDOWED
5. SEPARATED
6. COHABITING

Do you have any children?
1. YES
2. NO

If you do have children are/ were they:
1. NATURALLY CONCEIVED
2. ADOPTED
3. CONCEIVED BY ARTIFICIAL INSEMINATION
4. STEP CHILD /STEP CHILDREN

Where do you live? (Please circle one)
1. METROPOLIS (over 100,000)
2. CITY (50,000-100,000)
3. SMALL CITY (10,000-50,000)
4. TOWN (2,500-10,000)
5. SMALL TOWN (UNDER 2,500)
6. RURAL, BUT NOT A FARM
7. ON A FARM

With whom do you live? (Please circle one)
1. BY YOURSELF
2. WITH ONE OR BOTH PARENTS
3. WITH YOUR SPOUSE
4. WITH A ROOMMATE
5. OTHER (please write in)

If you do not live with your parents, how far is your parents residence from yours?
1. LESS THAN 50 MILES
2. MORE THAN 50 MILES
3. MORE THAN 100 MILES
4. MORE THAN 200 MILES
5. OTHER (please specify)

What is your religion, if any? (Please circle one)
1. CHRISTIAN
2. CATHOLIC
3. JEWISH
4. MUSLIM
5. BUDDHIST
6. NONE
7. OTHER (please specify)

What is your occupation/profession? (Please write in)

Are you currently employed? (Please circle one)
1. YES
2. NO

How long have you worked at your current job? (Please circle one)
1. LESS THAN 1 YEAR
2. LESS THAN 2 YEARS
3. MORE THAN 2 YEARS
4. MORE THAN 3 YEARS
5. MORE THAN 4 YEARS
6. MORE THAN 5 YEARS

Are there conditions in your work environment that are bad for your health?
1. YES (Please describe)
2. NO

How many hours per week do you work? (Please circle one)
1. LESS THAN 10 HOURS
2. 10-20 HOURS
3. 20-30 HOURS
4. 30-40 HOURS
5. MORE THAN 40 HOURS
6. MY WEEKLY HOURS VARY (From to )
7. I WORK ONLY DURING THE SUMMER

Does your job require hard physical work? (Please circle one)
1. YES (Please describe)
2. NO

Are these conditions in your work environment that are bad for your health?
1. YES (Please describe)
2. NO
Which of these broad categories describes your total income before taxes in 1990?

1. LESS THAN $10,000
2. $10,000 TO $14,999
3. $15,000 TO $19,999
4. $20,000 TO $24,999
5. $25,000 TO $29,999
6. $30,000 TO $39,999
7. $40,000 TO $49,999
8. $50,000 TO $64,999
9. $65,000 OR MORE

What is your highest educational degree?

1. 8TH GRADE
2. 10TH GRADE
3. HIGH SCHOOL DIPLOMA OR EQUIVALENCY
4. ASSOCIATE, TWO YEAR, JUNIOR COLLEGE DEGREE
5. BACHELOR'S DEGREE
6. MASTER'S DEGREE
7. DOCTORATE
8. PROFESSIONAL (MD, DDS, et al)
9. OTHER ______________________ (Please specify)

Which of the following indicates your current educational status?

1. FULL TIME STUDENT
2. PART TIME STUDENT
3. I AM NOT A STUDENT
4. OTHER ______________________ (Please specify)

Health care costs are covered by different programs in various states. Please specify the names of the programs which cover your costs, including private insurance companies.

1. 
2. 
3. 
4. 

If you have health care insurance, the policy is: (Please circle one)

1. YOUR OWN
2. YOUR SPOUSE'S POLICY
3. YOUR SPOUSE'S POLICY
4. YOU HAVE NO HEALTH CARE INSURANCE
5. OTHER ______________________ (Please specify)

How far is the CF clinic from your home?

1. LESS THAN 50 MILES
2. MORE THAN 50 MILES
3. MORE THAN 100 MILES
4. MORE THAN 200 MILES
5. OTHER ______________________ (Please specify)

Who calls the CF clinic to schedule your appointments?

1. I SCHEDULE MY OWN APPOINTMENTS
2. MY MOTHER/FATHER
3. MY SPOUSE/MADE
4. A FRIEND
5. OTHER ______________________ (Please specify)

According to your family's birth order, you are the:

1. OLDEST
2. YOUNGEST
3. AN ONLY CHILD
4. A MIDDLE CHILD

At what age were you diagnosed as having CF? (Please write in)

______________________________

Do/did any of your siblings have CF?

1. YES
2. NO

How many of your siblings have/had CF?

1. NONE
2. ONE
3. TWO
4. THREE
5. MORE THAN THREE
6. I AM AN ONLY CHILD

Have you sought any psychological/psychiatric counseling during the past twelve months?

1. YES
2. NO

Who is the most helpful person in helping you solve everyday problems of living?

1. MOTHER
2. FATHER
3. BROTHER
4. SISTER
5. PEER (boyfriend, girlfriend, spouse, roommate, etc)
6. CLERGYMAN
7. PHYSICIAN
8. NURSE
9. SOCIAL WORKER
10. SCHOOL COUNSELOR
11. FRIENDS
12. PSYCHOTHERAPIST
13. OTHER

What is your highest educational degree?

1. 8TH GRADE
2. 10TH GRADE
3. HIGH SCHOOL DIPLOMA OR EQUIVALENCY
4. ASSOCIATE, TWO YEAR, JUNIOR COLLEGE DEGREE
5. BACHELOR'S DEGREE
6. MASTER'S DEGREE
7. DOCTORATE
8. PROFESSIONAL (MD, DDS, et al)
9. OTHER ______________________ (Please specify)

Which of the following indicates your current educational status?

1. FULL TIME STUDENT
2. PART TIME STUDENT
3. I AM NOT A STUDENT
4. OTHER ______________________ (Please specify)

Health care costs are covered by different programs in various states. Please specify the names of the programs which cover your costs, including private insurance companies.

1. 
2. 
3. 
4. 

If you have health care insurance, the policy is: (Please circle one)

1. YOUR OWN
2. YOUR PARENTS' POLICY
3. YOUR SPOUSES' POLICY
4. YOU HAVE NO HEALTH CARE INSURANCE
5. OTHER ______________________ (Please specify)

How far is the CF clinic from your home?

1. LESS THAN 50 MILES
2. MORE THAN 50 MILES
3. MORE THAN 100 MILES
4. MORE THAN 200 MILES
5. OTHER ______________________ (Please specify)
29. Have you been hospitalized in the past 12 months?
   1. YES
   2. NO

30. If yes, how many stays (in total) did you stay in the hospital?

31. Do you smoke? (Please circle one)
   1. YES
   2. NO

32. Do you live with someone who smokes? (Please circle one)
   1. YES
   2. NO

33. Does he/she smoke in your presence? (Please circle one)
   1. YES
   2. NO

34. What is your weight?

35. What is your height?

36. Do you belong to any CF self-help or support group?
   1. YES
   2. NO

37. Do you feel you know enough about CF?
   1. YES
   2. YES, BUT WOULD LIKE TO HAVE MORE INFORMATION
   3. NO, BUT NOT INTERESTED IN MORE INFORMATION
   4. NO, BUT I WOULD LIKE TO HAVE MORE INFORMATION

38. What can health professionals do better to help you manage your treatments and your daily life?
   Please voice your opinions and list your concerns.
Your contribution to this effort is very much appreciated. A summary of the results of this survey will be available at your cystic fibrosis clinic by June 1992.
Code Number: __________

Participating Cystic Fibrosis Centers

Ann Arbor, Michigan
Cincinnati, Ohio
Columbus, Ohio
Dayton, Ohio
Iowa City, Iowa
Lexington, Kentucky
Madison, Wisconsin
Milwaukee, Wisconsin
Minneapolis, Minnesota
Pittsburgh, Pennsylvania

This study was funded by:

Research Development Award
Center for Nursing Research
The Ohio State University
College of Nursing
Columbus, Ohio

Graduate Student Alumni Research Award
The Ohio State University
Columbus, Ohio

Epsilon Chapter, The Ohio State University
Sigma Theta Tau International
Columbus, Ohio

R.C. Bigelow, Inc.
Fairfield, Connecticut
Appendix B

IRBs Approvals
Research Involving Human Subjects

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research protocol:

89B0061 THE RELATIONSHIP OF LOCUS OF CONTROL, FAMILY TYPE, AND HEALTH MAINTENANCE BEHAVIORS IN ADULTS WITH CYSTIC FIBROSIS, Joanne S. Stevenson, Judith Kimchi, Life Span Process

THE BEHAVIORAL AND SOCIAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

APPROVED  DISAPPROVED
X  APPROVED WITH CONDITIONS*  WAIVER OF WRITTEN CONSENT GRANTED

* Conditions stated by the Committee have been met by the Investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Review Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: March 31, 1989   Signed: [Signature]

(Chairperson)
MEMORANDUM

From: Vincent V. Hamparian, Ph.D.
Chairperson, Human Subjects Research Committee

To: Judith Kimchi, RN

Date: July 17, 1991

Protocol #: 89HSE021

Your protocol entitled: RELATIONSHIP OF LOCUS OF CONTROL, FAMILY
TYPE AND HEALTH MAINTENANCE BEHAVIORS IN ADULTS WITH CYSTIC
FIBROSIS

has been reviewed and approved by the Human Subjects Research
Committee on July 16, 1991 - INTERIM PROGRESS REPORT

NOTE: It is the responsibility of the principal investigator to retain a copy of each signed consent form INDEFINITELY in a manner that maintains confidentiality. In the absence of the principal investigator, the appropriate director or chief must assume this responsibility.
March 25, 1991

Judith Kimchi, R.N., M.S.
Columbus Children's Hospital
Cystic Fibrosis Center
700 Children's Dr.
Columbus, Ohio 43205

Dear Ms. Kimchi:

At its regularly convened meeting on March 21, 1991, the Human Rights Committee (HRC) reviewed your research project "Examining Health Behaviors of Young Adults with Cystic Fibrosis (CF)" and it was approved by Expedited Review.

The HRC would appreciate receiving one copy of any publications or abstracts resulting from this project.

Under our General Assurance #M1230 with DHHS, annual review and approval of all ongoing research protocols is necessary. Therefore, by March, 1992, you should contact the Human Rights Committee office for instructions on how to submit your renewal. However, if any untoward results related to this research should occur, they must be reported to us immediately.

Sincerely,

Richard H. Michaels, M.D.
Chairman
Human Rights Committee (HRC)
THE UNIVERSITY OF MICHIGAN
Ann Arbor

April 25, 1991

RE: Health Behaviors of Young Adults with Cystic Fibrosis

INVESTIGATOR: J. Kimchi, R.N.,

Approved without modification

The Committee to Review Grants for Clinical Research and Investigation Involving Human Beings of the University of Michigan Medical School has met and considered the above named application.

The Committee is composed of seventeen members. Ten members of professorial rank represent the Departments of Anesthesiology, Internal Medicine, Obstetrics and Gynecology, Pediatrics, Psychiatry, and Surgery. Dr. Carl Cohen, Professor of Philosophy and Edward B. Goldman and Dinah Seiver, Hospital attorneys serve as representatives of a non-health related discipline. The Reverend Kenneth Phifer serves as the non-University affiliated member. Ann Munro serves as the non-science related representative. Burgunda W. Volger, Pharm.D. is the Pharmacy representative. Christine W. Willis, R.N. is the Nursing representative.

Upon review of the above application the Committee has determined independently that the rights and welfare of the individuals involved in this research are carefully guarded. The methods used to obtain informed consent are appropriate. EACH INVESTIGATOR IS REQUIRED TO INFORM THE COMMITTEE PROMPTLY OF ANY CHANGE IN RESEARCH PROTOCOL OR ANY UNANTICIPATED NEGATIVE CHANGE IN THE HEALTH OR BEHAVIOR OF A SUBJECT THAT MAY BE ATTRIBUTABLE TO THE RESEARCH. The investigator agrees to retain in his files the written consent form signed by each participant. The investigator agrees to resubmit this application for continued approval in April, 1992.

Investigator's signature

William W. Coon, M.D., Chairman

Giles G. Boie, M.D., Interim Dean
University of Michigan Medical School

William C. Kelly, Ph.D.
Interim Vice President for Graduate Studies and Research
University of Michigan
ON 10/15/91, THE MEDICAL INSTITUTIONAL REVIEW BOARD APPROVED YOUR PROTOCOL AND CONSENT FORM ENTITLED:

Health Behavior of Young Adults with Cystic Fibrosis

Approval is effective from 10/15/91 until 10/14/92. Prior to the end of this period, you will be sent a Continuation Review Report Form which must be completed and returned to the Research Subjects Office so that the protocol can be reviewed and approved for the next period. This applies only to full and expedited reviews.

In implementing the research activities, you are responsible for complying with IRB decisions, conditions, and requirements. The research procedures should be implemented as approved in the IRB protocol.

Attached for your review is a booklet describing investigator responsibilities after IRB approval has been obtained. Please read the information carefully and retain a copy for your files. If you have questions or need additional information, contact the IRB Office at 257-8295 (Medical) and 257-3138 (NonMedical).
POLICY: A research activity involving human subjects that is not exempt from HHS regulations may not be funded unless an Institutional Review Board (IRB) has reviewed and approved the activity in accordance with Section 474 of the Public Health Service Act as implemented by Title 45, Part 46 of the Code of Federal Regulations (45 CFR 46—as revised). The applicant institution must submit certification of IRB approval to HHS unless the applicant institution has designated a specific exemption under Section 46.101(b) which applies to the proposed research activity. Institutions with an assurance of compliance on file with HHS which covers the proposed activity must submit certification of IRB review and approval with each application. (In exceptional cases, certification may be accepted up to 60 days after the receipt date for which the application is submitted.) In the case of institutions which do not have an assurance of compliance on file with HHS covering the proposed activity, certification of IRB review and approval must be submitted within 30 days of the receipt of a written request from HHS for certification.

1. TITLE OF APPLICATION OR ACTIVITY
Health Behaviors of Young Adults with Cystic Fibrosis

2. PRINCIPAL INVESTIGATOR, PROGRAM DIRECTOR, OR FELLOW
Judith Kimchi, RN, MS (The Ohio State University); Miles Weinberger, M.D. (University of Iowa)

3. FOOD AND DRUG ADMINISTRATION REQUIRED INFORMATION (see reverse side)

4. HHS ASSURANCE STATUS
☐ This institution has an approved assurance of compliance on file with HHS which covers this activity.

☐ No assurance of compliance which applies to this activity has been established with HHS, but the applicant institution will provide written assurance of compliance and certification of IRB review and approval in accordance with 45 CFR 46 upon request.

☐ Human subjects are involved, but this activity qualifies for exemption under 46.101(b) in accordance with paragraph ________ (insert paragraph number of exemption in 46.101(b), 1 through 3), but the institution did not designate that exemption on the application.

5. CERTIFICATION OF IRB REVIEW OR DECLARATION OF EXEMPTION
☐ This activity has been reviewed and approved by an IRB in accordance with the requirements of 45 CFR 46, including certification of all investigational new drug or device. (See reverse side of application.)

☐ The activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by 45 CFR 46 will be reviewed and approved before they are initiated and that appropriate further certification (Form HHS 556) will be submitted.

☐ Full Board Review
☐ Expanded Review

☐ Date of IRB review and approval. (If approval is pending, write "pending." Followed certification is required.) 4/8/91

☐ The activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by 45 CFR 46 will be reviewed and approved before they are initiated and that appropriate further certification (Form HHS 556) will be submitted.

☐ Human subjects are involved, but this activity qualifies for exemption under 46.101(b) in accordance with paragraph ________ (insert paragraph number of exemption in 46.101(b), 1 through 3), but the institution did not designate that exemption on the application.

6. Each official signing below certifies that the information provided on this form is correct and that each institution assumes responsibility for assuring required future reviews, approvals, and submissions of certification.

APPLICANT INSTITUTION
NAME, ADDRESS, AND TELEPHONE NO.
University of Iowa
Iowa City, Iowa 52242
Telephone: (319) 335-2123

NAME AND TITLE OF OFFICIAL (Ann or type)
James D. Morrison
Vice President for Research

SIGNATURE OF OFFICIAL LISTED ABOVE (Ann or type)
Carol Braddock (Acting)

COOPERATING INSTITUTION
NAME, ADDRESS, AND TELEPHONE NO.

NAME AND TITLE OF OFFICIAL (Ann or type)

SIGNATURE OF OFFICIAL LISTED ABOVE (Ann or type)
Research Involving Human Subjects

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research protocol:

89B0061  THE RELATIONSHIP OF LOCUS OF CONTROL, FAMILY TYPE, AND HEALTH MAINTENANCE BEHAVIORS IN ADULTS WITH CYSTIC FIBROSIS, Joanne S. Stevenson, Life Span Process

THE BEHAVIORAL AND SOCIAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

 ___ APPROVED
 ___ DISAPPROVED
 ___ APPROVED WITH CONDITIONS*
 ___ WAIVER OF WRITTEN CONSENT GRANTED

* Conditions stated by the Committee have been met by the Investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Review Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: December 6, 1991  Signed: Patricia M. Anderes
(Chairperson)
July 17, 1991

Judith Kimchi
Cystic Fibrosis Ctr/Children's
700 Children's Drive
Columbus OH 43085

RE: "Health Behaviors of Young Adults with Cystic Fibrosis"

HUMAN SUBJECT CODE NUMBER: 91053930

Dear Judith Kimchi:

The Committee on the Use of Human Subjects in Research has received your response to its stipulations. Since this information satisfies the requirements set by the Committee, final approval for the project is noted in our files.

The above code number is assigned to your research. That number, along with the title of your study, must be used in all communication with the Committee office.

For your records, and for grant certification purposes, the approval date for the referenced project is June 11, 1991.

It is the responsibility of the principal investigator to bring to the attention of the Committee any proposed changes in the research project, prior to their initiation, that will affect human subjects. Research subjects are subject to annual review and renewal.

Upon receipt of this letter, you may begin your research. If you have questions, please call me at (612) 624-9829.

The Committee wishes you every success with this research.

Sincerely,

Ellen Stewart
Executive Assistant

EHS/cdl

ADVISOR CC: Joanne Stevenson
CC: Warren J Warwick
NOTICE OF APPROVAL

Meeting Date February 18, 1991  Protocol Number 01-708-000
(Refer to this number when making inquiries)

TO: Judith Kimchi
Columbus Children's Hospital
Dept. of Pediatric Surgery
700 Children's Drive, Columbus, OH 43205

FROM: Jane C. Fitch
IRB Administrator

RE: Protocol entitled, "Health Behaviors of Young Adults with Cystic Fibrosis"

The Human Subjects Committee has reviewed and approved the research protocol referenced above. Please note the following additional information and requirements:

INSTITUTIONAL ENDORSEMENT: If a granting agency requires notification of HSC approval, submit the name and address of an individual at the agency.

ADVERSE REACTIONS: If any serious, unexpected adverse reactions occur as a result of this study, you must notify the IRB Administrator immediately.

AMENDMENTS: If you wish to change any aspect of the study (such as design, procedures, consent forms, or subject population), please submit your requested changes, using a Change of Protocol form, to the administrator. The new procedure may not be initiated until HSC approval has been given.

RENEWAL: You are required to apply for renewal of approval every year for as long as the study is active. Contact the HSC office for renewal forms.

TERMINATION OF RESEARCH PROJECT: Please promptly notify the HSC of the termination of this project.

CONSENT FORMS: All subjects should be given a copy of the consent form(s).

The HSC suggests that you keep this memo with your copy of the approved protocol.

6/5/91 - Initial Review
JCF/cw
06561 xc: Dr. Mischler
Appendix C

Formulas for Present Predicted FEV1 and FVC
PREDICTION EQUATIONS

Following is a listing of the two sets of prediction equations provided by 560 software. Option #1 includes the equations of Morris and Cherniack. Option #2 includes the equations from Knudson's 1983 study. These options are selectable in the Configuration Program.

When two equations are given, the first applies to males, the second to females. Additionally, H = height in inches and A = age in years.

OPTION #1

† ADULTS

† Morris (1)

FVC and SVC (L) = 0.148H - 0.025A - 4.24
0.115H - 0.024A - 2.05

FEV1 (L) = 0.092H - 0.032A - 1.26
0.089H - 0.025A - 1.93

FEV3 (L) = 97% of VC

FEF 25-75% (L/sec) = 0.047H - 0.045A + 2.51
0.060H - 0.030A + 0.551

Kory (2)

FEV0.5 (L) = 0.050H - 0.024A + 0.24
0.046H - 0.011A - 0.3

Cherniack (3)

PEFR (L/sec) = 0.144H - 0.024A + 0.225
0.090H - 0.018A + 1.13

FEF 25% (L/sec) = 0.090H - 0.020A + 2.726
0.069H - 0.019A + 2.147

FEF 50% (L/sec) = 0.065H - 0.030A + 2.403
0.062H - 0.023A + 1.426

FEF 75% (L/sec) = 0.036H - 0.041A + 1.984
0.023H - 0.035A + 2.216

MVV (L/min) = 3.03H - 0.816A - 37.9
2.14H - 0.685A - 4.87

7-8
Bates (4)

\[
\begin{align*}
\text{FRC (L)} &= 0.130H - 5.16 \\
&\quad 0.119H - 4.85
\end{align*}
\]

Goldman (5)

\[
\begin{align*}
\text{RV (L)} &= 0.069H + 0.017A - 3.45 \\
&\quad 0.081H + 0.009A - 3.90
\end{align*}
\]

Gaensler (6)

\[
\begin{align*}
\text{S.B.DLCO} &= 0.250H - 0.177A + 19.93 \\
(\text{ml/min/mmHg}) &= 0.284H - 0.117A + 7.72
\end{align*}
\]

CHILDREN

Dickman, Schmidt, Gardner (7)

(for children 42 through 59 inches tall, 5 through 17 years)

\[
\begin{align*}
\text{FVC and SVC (L)} &= 0.094H - 1.04 \\
&\quad 0.077H - 2.37
\end{align*}
\]

\[
\begin{align*}
\text{FEV1 (L)} &= 0.085H - 2.86 \\
&\quad 0.074H - 2.48
\end{align*}
\]

\[
\begin{align*}
\text{FEF 25\%-75\% (L/sec)} &= 0.094H - 2.61 \\
&\quad 0.087H - 2.39
\end{align*}
\]

\[
\begin{align*}
\text{PEFR (L/sec)} &= 0.161H - 5.88 \\
&\quad 0.130H - 4.51
\end{align*}
\]

\[
\begin{align*}
\text{MVV (L/min)} &= 3.81H - 134
\end{align*}
\]

(for children 60 through 78 inches tall, 5 through 17 years)

\[
\begin{align*}
\text{FVC and SVC (L)} &= 0.174A + 0.164H - 9.43 \\
&\quad 0.102A + 0.117H - 5.87
\end{align*}
\]

\[
\begin{align*}
\text{FEV1 (L)} &= 0.121A + 0.143H - 7.86 \\
&\quad 0.085A + 0.100H - 4.94
\end{align*}
\]

\[
\begin{align*}
\text{FEF 25\%-75\% (L/sec)} &= 0.126A + 0.135H - 6.50 \\
&\quad 0.083A + 0.093H - 3.50
\end{align*}
\]

\[
\begin{align*}
\text{PEFR (L/sec)} &= 0.205A + 0.181H - 9.54 \\
&\quad 0.139A + 0.100H - 4.12
\end{align*}
\]

7-9
Appendix D

Letters to Participants
Consent Forms
Letter to a participant with CF

Judith Kimchi, RN, MS
The Ohio State University

Date

Dear __________

I am conducting a study of young adults who have Cystic Fibrosis (CF) under the direction of Dr. Joanne Stevenson. The purpose of this study is to learn about the views of adults with CF on health-related issues, their own health, and their families of origin. Thus, I would like to hear what you think about your health, and how you manage your own condition. I would also like to learn about your family of origin (your parents). The ultimate purpose of the study is to gain knowledge about adults with CF which will help nurses better serve the needs of adult clientele with CF.

For the purpose of this study, you have been selected from the group of adults with CF who attend ________ clinic, to represent that group. I hope you will be willing to participate. However, non-willingness to participate will NOT have any bearing on your relationship with the health team at the clinic.

The enclosed booklet contains 83 questions, which should take no longer than 20-30 minutes to complete. The questions are easy to answer and there are no right or wrong answers. The right answer is only what you think is right.

All the information you provide will remain confidential. The code number on the booklet is for the purpose of keeping track of the returned mail. The information will NOT be shared with any member of the clinic staff. Your participation is important and will be greatly appreciated. Please sign this letter and return it with the completed questionnaire. I will be happy to share the final results with you. If you would like a copy please indicate so in the booklet. Thank you.

Sincerely,

Judith Kimchi, RN, MS

Consent: I have read the information given above. I understand the meaning of the information and that Dr. Grum will be available at 936-5040 and Ms. Carol Campbell, coordinator of CF center will be available at 763-2567 to answer any additional questions. I hereby consent to participate in the study.

_________________________   ________________
Signature          Date
November 11, 1991

Dear prospective participant,

After a careful examination of our young adult patients list, you have been selected as a possible participant in a study conducted by J. Kimchi, RN, MS who is a doctoral candidate at the Ohio State University, Columbus, Ohio. The purpose of this study is to learn about the views of adults with CF on health related issues, their own health, and their family of origin.

We have reviewed Mrs. Kimchi's study and would like to encourage you to participate. The knowledge gained from the study about young adults with CF will help nurses better serve the needs of adult clientele with CF. A booklet with questions is enclosed. The questions are easy to answer and there are no right or wrong answers. If you agree to participate, please complete the booklet and mail it back in the stamped addressed envelope provided in your packet. Your answers will be kept confidential and your participation is strictly voluntary. The code number on the booklet and envelopes are for the purpose of keeping track of the return mail. The information will NOT be shared with members of the clinic staff. A summary of the results will be available in our clinic by June 1992.

If you have any questions regarding the study please don’t hesitate to contact us at (513) 559-6771 or J. Kimchi at (614) 461-6787. Thank you.

Sincerely,

Robert Wilmott, MD
Director, Cystic Fibrosis Center

Kim Bivens, RN, MSN
Cystic Fibrosis Center
CONSENT

Dear prospective participant,

I am conducting a study of young adults who have Cystic Fibrosis (CF) under the direction of Dr. Karen McCoy. The purpose of the study is to learn about the views of adults with CF on health-related issues, their own health, and their families of origin. Thus, I would like to hear what you think about your health, and how you manage your own condition. I would also like to learn about your family of origin (your parents). The ultimate purpose of the study is to gain knowledge about adults with CF which will help nurses better serve the needs of the adult clientele with CF.

For the purpose of this study, you have been selected from the group of adults with CF who attend a CF clinic, to represent that group. I hope you will be willing to participate. However, nonwillingness to participate will NOT have any bearing on your relationship with the health team at the clinic. Participation is totally voluntary.

The enclosed booklet contains questions which should take no longer than 20-25 minutes to complete. The questions are easy to answer and there are no right or wrong answers. The right answer is only what you think is right.

All the information you provide will remain confidential. The code number on the booklet is for the purpose of keeping track of the returned mail. The information will NOT be shared with any member of the clinic staff. Your participation is important and will be greatly appreciated. A summary of the results will be available in your cystic fibrosis clinic by June 1992. Thank you.

Sincerely,

Judith Kimchi, RN, MS

I have read the information given above. I understand the meaning of the information and that Dr. McCoy is available at (614)461-6819 to answer any additional questions. I hereby consent to participate in the study.

____________________________________  __________________________
Signature                                      Date
Appendix E

Copyright Permissions
To: Fellow Health Researcher  
From: Kenneth A. Wallston, Ph.D.

Thank you for your interest in the Health Locus of Control Scales. Please excuse this form response, but I have so many inquiries requiring similar replies that I have found this to be an efficient means of disseminating information.

You have my permission to utilize Form A or B of the MHLC scales in any health-related research you are doing. My only request is that you keep me informed of any results you obtain using the scales. In that way I hope to continue to serve as a clearinghouse for information about the scales.

We are currently in the process of developing Form C of the MHLC scales, an instrument which can easily be made specific to any existing medically-related condition which your subjects might have (e.g., diabetes, cancer, high blood pressure, migraine headaches, arthritis, chemical dependencies, etc.). We have used Form C as an "Arthritis Locus of Control Scale" and are generally pleased with its psychometric properties. If you think such an instrument would be helpful in your research and if you are willing to share your data back with us, we would be pleased to make it available to you.

We have put many of the studies that have been done with the HLC/MHLC scales on a computerized database coded into 22 different fields. Thus, should you or any other investigator wish to know "how many studies have been done using Form A with an N > 100 with male subjects predicting smoking behavior," we have the capability of searching the database and seeing which studies fit that description. There is a charge of $25 for each search and report that we do; however, we will refund $20 if the search comes up with nothing useful.

If you wish to be added to our mailing list or want additional material, please complete and return the enclosed interest questionnaire. For some items there is a small charge to cover duplication and postage. I hope to periodically send updated information related to the use of these scales as it becomes available.

If you have more specific questions, don't hesitate to contact me. Please remember to send me information on any use you make of these scales. I have included a usage questionnaire to facilitate your doing so. I look forward to hearing from you.

2/89
PERMISSION TO USE FACES III

I am pleased to give you permission to use FACES III in your research project, teaching, or clinical work with couples and families. You can either duplicate the materials directly or have them retyped for use in a new format. If they are retyped, acknowledgement should be given regarding the name of the instrument, the developer’s name, and the University of Minnesota.

In exchange for providing this permission, we would appreciate a copy of any papers, thesis, or reports that you complete using these inventories. This will help us in staying abreast of the most recent development and research with these scales. Thank you for your cooperation.

In closing, I hope you find FACES III of value in your work with couples and families. I would appreciate hearing from you as you make use of this inventory.

Sincerely,

David H. Olson, Ph.D.
Professor

FAMILY INVENTORIES PROJECT (FIP)
Director: David H. Olson, Ph.D.