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THE UNIVERSITY OF ALBERTA

FAMILY FUNCTIONING WITH CYSTIC FIBROSIS

by

BARBARA R. WHEATLEY

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
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Date: April 3/84

DEDICATION

to

Minnie Louise Thompson

Lena Petrowski Purin

Carolen Thompson Purin

for their gifts of inspiration, wisdom and love.

ABSTRACT

The use of systems theory in the understanding of family functioning has recently led to an increase in knowledge about the characteristics associated with family functioning. In this study these characteristics were grouped into three areas: boundaries between the family and other groups in society and among subgroups in the family, feedback, and personal resources of family members. The application of this knowledge to families with a chronically ill child is but one example of a shift by health care professionals from a focus on individual pathology to one of family strengths.

The purpose of the study reported here was to determine which characteristics were associated with family functioning in families with members with Cystic Fibrosis (CF). The understanding of family functioning in these particular families is crucial because the disease is chronic, because more than one child may be affected and because family members may spend up to several hours per day in treatment of the CF child(ren).

The sample consisted of 29 families drawn from the population of all CF families in Northern Alberta who were on the mailing list of the Edmonton CF Chapter. Husbands and wives of the participating families completed four questionnaires: the Family Functioning Index (FFI), the Family Environment Scale (FES), the Family Inventory of Resources for Management (FIRM) and a demographic questionnaire. Correlations were calculated between the FFI and measures of family interaction and resources taken from the other three instruments.

Findings from this study are that resources associated with

family functioning in CF families are somewhat different than models of optimal family functioning would indicate. The families had boundaries which were relatively closed, highly cohesive internal relationships, and structured organization with clear role division. Whereas in some families such organization would be considered dysfunctional, in this study it was associated with high levels of family functioning.

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CHAPTER I

STATEMENT OF THE PROBLEM

Rationale

Cystic Fibrosis (CF), an inherited disorder of the exocrine glands for which the underlying cause remains unknown, is characterized by varying degrees of chronic and recurrent pulmonary infections. The treatment, sometimes requiring from one to several hours daily, is carried out at home by family members, potentially placing considerable stress upon the family system. While the prognosis for those with CF has improved, CF is still considered to be a progressive and fatal disease. Although improved treatment has extended the life span of individuals with CF, the families are still confronted with constantly changing treatment regimes and the impending death of their family member with CF.

Traditionally, researchers and practitioners have focussed on the individual with CF and have not considered the family unit. Physicians have typically been concerned with the physical welfare of the individual with CF and medical social workers have attended to the provision of family support for the member with CF. Researchers have studied clinic samples and have tended to study separately the pathology of CF individuals and other members of the family rather than the potential strength of the entire family as a unit. Because of the quest for the underlying cause of CF and in the attention given to the immediate needs for physical care, only recently has the importance of focussing on family dynamics and relationships become apparent.

While working with families with a CF member, this author was struck by the incongruity between reports in the literature indicating that such families did not function well and her own personal observation that many of these families appeared to be functioning well. There appears to be little published material about the characteristics of those families which do function well.

The significance of this research is that the identification of the characteristics which are associated with coping, adapting, and psychosocial growth within families with a CF member will be of value to both health personnel who are in contact with them and to the families themselves. Such knowledge of family functioning would also be useful to the health care personnel dealing with any family.

Assumptions

1. From a systems theory perspective, the family with a CF member, hereinafter referred to as "CF family," is a system in which there are subsystems (eg. individual, marital, sibling, etc.) relating to each other and to other systems outside the family (eg. the extended family, school, church, etc.), and in which one part of the family should not be understood in isolation from the rest of the system.
2. There is a range of levels of family functioning as measured by the Family Functioning Index.
3. The development of a profile of characteristics of high functioning CF families will be useful to various professionals who work with such families.

Limitations

1. Only families with two parents present in the home were selected to participate in the study. As the children in these families were not interviewed, only the parents' perception of family functioning was studied. (The mothers and fathers are referred to as men and women in this study.)
2. Participating families had at least one living member with CF.
3. The study was cross-sectional in nature.
4. The response rate was 40%.

Research Questions

1. What are the individual and family characteristics of the study sample of CF families?
2. What is the nature of the contact by these families with other systems (health care, church, school, recreation)?
3. What is the range of family functioning of the families?
4. What individual, family, and between system variables of the families correlate with family functioning?

Statement of Purpose

The purpose of this study was to determine what characteristics of CF families were associated with family functioning. Knowledge about CF family characteristics which are associated with coping, adaptation and psychosocial growth could be of assistance to families and health care personnel involved in the development of appropriate

planning and intervention strategies.

Definition of Terms

Family functioning includes all of those activities and relationships among family members (eg. communication, roles, problem-solving, decision-making, affective responsiveness and involvement, and behaviour control) which enable the social, the psychological and the physical development and maintenance of family members in an open system. There is a wide range of family functioning. For the purpose of this study, family functioning was measured by the Family Functioning Index.

CHAPTER II

THEORETICAL FRAMEWORK

The theoretical framework chosen for this study was Systems Theory based on the work of Bertalanffy (1969), Buckley (1967) and Hill (1972). Systems theory is useful to gain an understanding of individuals in the context of the social systems of which they are a part, and to view individuals in their subsystems in relation to other systems inside and outside the family. A system has structure and function and may be defined as a set of components or units interacting with each other within a boundary which filters both the type and speed of the flow of inputs and outputs through feedback. Systems theory provides a basis for understanding the concept of social support in which individuals are cared for, loved and esteemed as members of a network of mutual obligations (Caplan, 1974; Clinebell, 1981; Cobb, 1976).

Every family may be regarded as a system with many interrelationships all of which may be affected by events and actions with systems outside the family such as school, place of work, church, hospital, etc. (See Figure 1).

Definition of Family

In family systems theory, a family is defined as a group of individuals who interact within usually non-verbally agreed upon rules or patterns of behaviour. These behaviours have a limited range of flexibility. The family as a social system places certain limitations

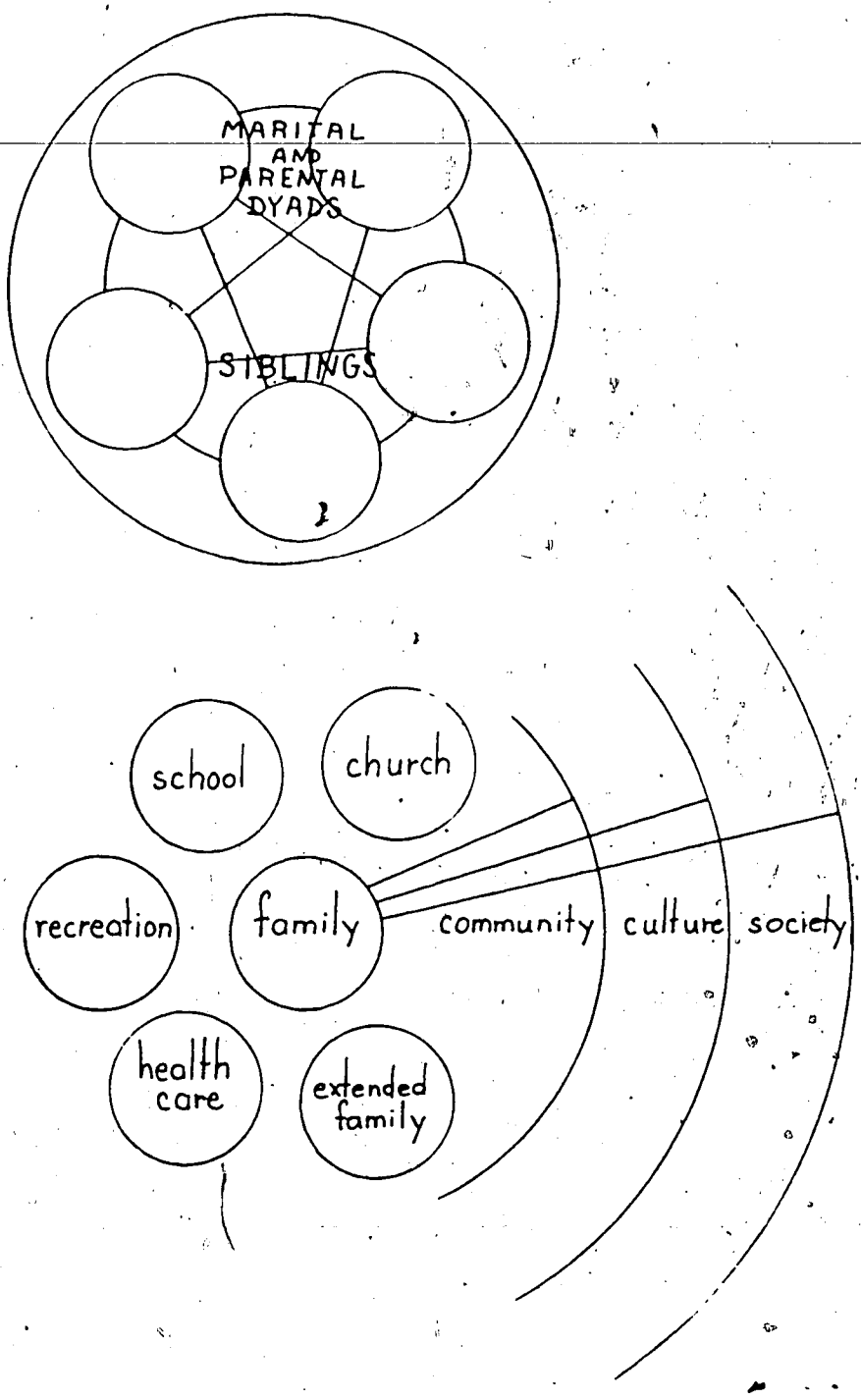


Figure 1: The Family System and Outside Systems.

and rewards on its members, and requires some degree of equilibrium for its functioning (Satir, 1972; Dodson, 1977).

The family system is itself composed of several subsystems, all interacting with each other and with the outside environment (Kantor & Lehr, 1975). Of these interdependent, interacting subsystems, the most enduring are those of the spouse, the parents and the siblings. Since each family member belongs to several subsystems simultaneously, he or she enters into different complementary relationships with other family members. The basic subsystem in the family is the husband-wife relationship and consequently any dysfunction therein tends to reverberate throughout the family system (Satir, 1964). The strengths or weaknesses within this spousal subsystem have a major effect upon the learned attitudes of the other family members and influence their acquisition of communication and problem-solving skills. The parental subsystem is involved with the nurture, guidance and control of children. The sibling subsystem is the child's first peer group in which major patterns of negotiating, cooperating and competing are learned (Goldenberg & Goldenberg, 1980).

Although theorists use a number of different terms to describe the characteristics of families, the emphasis tends to be on structure and function. The former refers to the organization of the family, particularly the positions of the family members relative to each other, and the latter to the performance of tasks (practical, social and psychological) carried out by individual family members in the service of maintenance of the family system. In families, as with other systems, structure may be understood in terms of the systems

concept of boundaries which are the interface between systems and which vary in permeability from closed to open. Guidelines evolve to regulate what passes back and forth over the borders both amongst intrafamily subsystems and between the family and systems outside the family. Function may be understood by the systems term feedback, a process in which a system influences its members as to how to relate to each other and to the outside environment. As a result of effective feedback, it is possible for families to make changes in and maintain a desired state of functioning.

Boundaries and the Family

An important premise of the systems theory is that boundaries provide structure at any level within a system and are the rules which govern who participates in family systems and in what way (Minuchin, 1974). Boundaries create and maintain a family territory within the larger community environment by regulating both incoming and outgoing information. Through boundary maintenance, a system filters out external elements seen as hostile to system goals while incorporating those elements seen as helpful to the pursuit of those goals (Hall & Weaver, 1977; Kantor & Lehr, 1975). The issue of boundaries is central to the study of CF families because there is an assumption that these families, in requiring a great deal of contact with other systems in order to carry out the daily care of the CF member, have relatively open boundaries.

Boundaries Within the Family

The degree of cohesiveness in a family can vary from enmeshment (ie. extreme bonding and limited individual autonomy) to disengagement of members (ie. individual independence or unconnectedness), as shown in Figure 2. Ideally, optimally functioning families will have a balanced degree of cohesion and can be described as separated or connected. Semi-open boundaries within a family allow a reciprocal flow of the new information necessary for making changes in such things as treatment of a family member who is ill.

Clear generational boundaries (Barnhill, 1979; Minuchin, 1974) as well as boundaries around functional subsystems such as the marital and parental dyads and sibling group are considered to be important in optimally functioning families. Coalitions or alliances between certain members of different generations may operate for the benefit of some members but not others. For example, where one parent is too absorbed with a child, the marital relationship or relationship with other children may be adversely affected.

Boundaries Outside the Family

The degree to which a family's systems boundaries are open or closed to other systems may be an important determinant of effective family functioning. Family systems which have semi-permeable boundaries are able to link with outside systems such as the extended family, community groups, school, church and the health care delivery system for support and resources which may be an asset for optimal family functioning.

Four Levels of Cohesion

	Disengaged	Separated	Connected	Enmeshed
Boundaries	Open external boundaries. Closed internal boundaries. Rigid generational boundaries.	Semi-open external and internal boundaries. Clear generational boundaries.	Semi-open external boundaries. Open internal boundaries. Clear generational boundaries.	Closed external boundaries. Blurred internal boundaries. Blurred generational boundaries.
Coalitions	Weak coalitions, usually a family scapegoat.	Marital coalition clear.	Marital coalition strong.	Parent-child coalitions.

(from Olson & McCubbin, 1981)

Figure 2: Some Interrelated Concepts of Cohesion

Boundaries and CF Families

The permeability of boundaries in CF families may be seen as crucial since, in order to care for their CF members, such families must have frequent contact with outside systems, in particular, the health care system. Traditionally itwas expected that CF families turn to other sources of support such as the extended family in order to maintain optimal family functioning. In these families the degree of closeness within family subsystems such as the marital partnership or the parent-child combinations can be affected by the presence of a CF member. While clear intrasystem boundaries between family members are desirable, the quantity and quality of relationships may differ due to the time and care requirements of the CF member.

Feedback and the Family

Family functioning consists of those activities and relationships among and between persons and the environment which enable the family to maintain itself as an open system. Families use feedback from within the family and from systems outside the family to maintain their level of functioning. Feedback, which is an ongoing process, is used by people in a system to adjust future conduct based on past performances. The process involves rules which determine patterns of interaction and which are main indicators of a system's functioning (Olson, et al., 1979).

Families require a certain degree of adaptability in order to change in response to developmental or environmental input. Adaptation occurs through such mechanisms as positive and negative feedback

loops. Negative feedback maintains steady states in systems. In positive feedback a steady state is not maintained, rather, the initial output is continually amplified unless the process is self-limiting (Watzlawick, et al., 1967). Interchange between systems includes getting and using valuable information and material and eliminating patterns and beliefs that are no longer adaptive.

How people in a system monitor their own progress toward a goal, correct and add to their response, and then change their goal, depends on the level of feedback at work. Level one or simple feedback is a circular process in which output is subsequently processed as input. Families operating at level one have no mechanisms to deal with new information or to develop new rules. Their limited repertoire of responses is often inadequate to deal with the new information required to care for a family member with a chronic illness.

At level two feedback, another level of complexity is added for stable system operation. Input is compared to the existing family standard and an adjustment is made in the system to correct any deviation from that standard. People in the system at this level have more rules from which to choose, enhancing their adaptability (Broderick & Smith, 1979).

When a family operating at level three perceives that the usual range of corrective responses is ineffective, it creates new rules or more innovative responses to set the family back on course toward its goals. Level three is seen as the optimal level of functioning for families dealing with new information.

The degrees of response to information and the amount of rule change in the various levels of feedback are discussed by Olson & McCubbin (1981). Four levels of adaptability ranging from chaotic to rigid are presented in their typology. Ideally, optimal family functioning will occur between the levels of flexible and structured adaptability in which roles, rules and feedback can be modified to accommodate new information or changes in the system (see Figure 3).

The ability to deal with change is certainly required of CF families. The treatment regime involves therapy on a daily basis and may be provided by various family members who must regularly deal with new information as the disease condition of the CF member changes. CF families require the ability to appropriately adapt role relationships and relationship rules by seeking out new alternatives in response to situational or developmental changes. Such families may tend to be more structured than flexible in adapting to the somewhat demanding nature of the daily treatment regime.

Adaptability may be observed in the way the family organizes itself to care for the CF member. For example, it might be argued that the time consuming task of care might best be provided by a parent at home full time, supported by a full time member of the work force. In this case a highly structured family with clear role division would be most functional.

The Individual and the Family System

Interrelationships between an individual's psychological experiences, family relationships and experiences with the wider

Four Levels of Adaptability

	Chaotic	Flexible	Structured	Rigid
Roles	Dramatic role shifts.	Role making and sharing. Fluid change of roles.	Some role sharing.	Role rigidity. Stereotyped roles.
Rules	Dramatic rule shifts. Many implicit rules. Few explicit rules. Arbitrarily enforced rules.	Some rule changes. More implicit rules. Rules often enforced.	Few rule changes. More explicit than implicit rules. Rules usually enforced.	Rigid rules. Many explicit rules. Few implicit rules. Strictly enforced rules.
System Feedback	Primarily positive loops; few negative loops.	More positive than negative loops.	More negative than positive loops.	Primarily negative loops. Few positive loops.

(from Olson & McCubbin, 1981)

Figure 3: Some Interrelated Concepts of Adaptability

socio-economic systems are complex and cannot be ignored. Systems theory represents a change from considering individuals as isolated units to viewing them in relation to their functions and to other individuals.

Family functioning is not based solely upon family resources. At the individual level, personal assets such as age, gender, education and occupation may affect the nature of what goes on in the family. For example, there may be costs to a family in terms of individuation and personal growth for women, (who in CF families are likely to be the main caregivers) as they abandon personal or career goals. It may be expected that womens' more than mens', personal resources would be related to optimal family functioning, because women tend to be more central to caregiving. Men (who are likely to be the main wage earners) may also abandon personal goals or career mobility to remain near the required facilities for treatment of CF or to share in some of the care of the family member with CF.

In CF families, health problems may not be restricted to CF members. The physical and time demands of the CF treatment regime may potentially increase the stress experienced by caregivers and their supporters which may in turn affect the care given to the CF member. The meeting of physical and emotional needs of all family members is an important consideration, if families are to function optimally.

CF families, comprised of individuals with their many relationships inside and outside the family, are systems with structure and function. Using the systems theory concepts of boundary and feedback, men and women in these families were investigated to

delineate family and individual characteristics which may relate to family functioning.

CHAPTER III

LITERATURE REVIEW

The literature reviewed for this study includes that of optimal or healthy family functioning and the nature of Cystic Fibrosis. The latter is subdivided using the systems concept of boundary and feedback to explore existing information on CF families.

The Nature of Family Functioning

Family functioning consists of those activities and relationships among and between persons and their environment which enable families to be maintained as open systems (Roberts & Feetham, 1982). It also includes the stabilization and enhancement of growth of adult members as well as the provision of context for growth and development of children. In any complex family system, family functioning includes such dimensions as roles and rules, problem-solving, decision-making, communication, range of emotions, power and authority, individuality and individuation, as well as a variety of family environments (Deykin, 1972; Moos, 1976; Epstein, et al., 1978; Cocivera, 1981).

Optimal Family Functioning

Although more has been written in the literature about negative factors in family functioning which contribute to the various societal problems of delinquency, poor mental health and family breakdown, a recent shift in orientation among some family systems researchers has resulted in the burgeoning of theoretical material on the characteris-

tics of well or optimally functioning families. Many different terms are used to describe such families: adequate family functioning (Glasser & Glasser, 1970); self-actualized or "growing" families (Satir, 1972); flexible, adaptable, goal achieving systems (Beavers, 1977); healthy family mental health (Barnhill, 1979); effectively functioning families (Klein & Hill, 1979); strong families (Stinnett, 1980; Bownman, 1981); and optimally functioning families (Beavers, 1981). The latter term was chosen. Because of the theoretical framework used for this study, information will be organized under the systems concepts of boundaries, feedback and individual elements (see Figure 4) to elaborate upon features of optimally functioning families.

Boundary Elements. There is general consensus among authors that cohesion, or a balance between separateness and connectedness among family members, as measured by such dimensions as independence, coalitions, boundaries, decision-making, recreation and emotional bonding, is desirable for optimal family functioning (Barnhill, 1975; Otto, 1975; Stinnet, 1980; Olson, 1981). Fisher, et al., (1982) in a survey of 208 non-clinical families reported that unity in the family was considered to be important by family members and that high value was placed on cohesion. In the six year Timberlawn study (Lewis, et al., 1976), optimally functioning families were found to have clear boundaries between members (intrasystem) where intimacy was attained by skillful communication and awareness of individual needs and boundaries. Such families were relatively open (Beavers, 1977), able to link to outside networks and interacted with the larger environment

	Stinnet 1980	Satir 1972	Lewis et al. 1976	Hill Robert 1971	Whit-aker 1980	Klein & Hill 1979	Otto 1975	Barn-hill 1975	Olson 1981
Boundary elements									
- Appreciation, mutual respect encouragement	*	*	*		*		*		
- Parental solidarity, growing with and through children			*				*		
- Clarity of family rules	*				*	*	*	*	*
- Kinship, support - Marital Coalition				*			*	*	*
- Cohesion, intra-family cooperation, security, bonding, mutuality, a sense of the whole, intrapyschic family (history, myths, stories) unity, loyalty, connectedness	*						*	*	*
- Linking to the outside, contact with network		*		*			*		
- Openness to new information	*	*	*		*	*	*	*	*
Feedback elements									
- Communication, shared meaning, clarity of roles, good patterns, availability	*	*	*		*	*	*	*	*
- Child rearing skills			*				*		
- Adaptibility, flexibility (developmentally and situationally) of roles, use of crises for growth			*	*	*	*	*	*	*
Individual Elements									
- Personal growth, self actualization		*							
- Spiritual, religious commitment	*	*		*			*		
- Physical and emotional needs met	*	*		*			*		
- Self-help ability and help acceptance							*		

Figure 4: Characteristics of Optimally Functioning Families Using Systems Theory Concepts

(Buckley, 1967; Satir, 1972). There appears to be no explicit set of assumptions about optimal family structure, although the nuclear family with two parents and children can be arguably seen as the cultural norm within the Western world.

Feedback Elements. Optimally functioning families have been found to have the capacity to accept directions, organize themselves in response to a task, develop input from others inside and outside the family and to negotiate differences. Such families seek and use new information and are able to discard previous and less adaptive patterns and beliefs (Lewis, et al., 1976; Beavers, 1977). In the same vein, Olson & McCubbin (1981) pointed out that an important factor in optimally functioning families was the family's ability to change its roles and rules in response to new situations by striking some balance between being structured and flexible.

The authors of literature on the optimally functioning family are also in agreement that communication skills are essential for families to balance cohesion and adaptability. Optimal families were found to be verbally open, direct and clear with little evidence of unresolved conflict (Lewis, et al., 1976).

Individual Elements. Individuals are open living systems, subsystems of other systems, with their own internal resources. They require a group or interpersonal matrix for the satisfaction of their human needs (Hall & Weaver, 1977). An individual may be viewed as an interrelated, interacting and interdependent part of the systems in which he or she functions and may be affected by psychosocial events and situations in the environments of those systems. Family

characteristics change as individuals in the family change, influenced by such factors as physical and mental health (Barnhill, 1975), age, economic status, leisure time, educational level, addition or loss of members, organizational skills, roles and rules which facilitate the potential for personal growth and self-actualization (Otto, 1975; Dodson, 1977), and spiritual commitment (Hill, 1971; Satir, 1972; Stinnet, 1980).

The review of literature on family strengths has been drawn from a survey of research conducted on families and has included a discussion of the ingredients which foster optimal functioning: the interrelationships inside and outside families, the ways families adapt, and the importance of individuals in a family.

The Nature of Cystic Fibrosis

Cystic fibrosis is a chronic, systemic, hereditary disorder of children, adolescents, and young adults in which a dysfunctioning of the body's exocrine glands detrimentally affects the respiratory and digestive systems. Chronic illness is defined in this study as "a disorder with a protracted course which can be progressive and fatal or associated with a relatively normal life span despite impaired physical or mental functioning" (McKeever, 1981, p. 124). CF, a progressive and eventually fatal illness, is characterised by varying degrees of severity of either lung deterioration or inability to digest food, or both. CF is genetically inherited (Mendelian recessive) with an incidence rate of one per two thousand population (Thompson, 1980). The incidence rate of the carrier state, which is undetectable, is one

per twenty population. When two carriers procreate, which occurs in one out of four hundred procreations there is a one in four chance that a CF child will result. CF cannot be diagnosed in utero. The CF member is dependent on others for daily treatment required to clear the lungs and to fulfill special nutritional requirements. Care is given mainly at home by the family and, depending on the severity of the disease, may be punctuated by few or many hospitalizations.

The Family and Cystic Fibrosis

The study of CF in a family context is appropriate because of the nature of the disease, its genetic implications and the time-consuming daily treatment given at home. Success of treatment and improved life expectancy may be dependent upon the family system's adaptation to the changing needs of the CF member. Home care, usually given by the parents, can require huge amounts of time and energy. This may mean a sacrifice of the time and energy usually spent on the maintenance of social and community networks. Pratt (1976) says that families may not reach outside their borders at a time when such contact would benefit the family system.

The presence of CF can affect other family members including the extended family. Families of origin may blame themselves or misunderstand the genetic aspects of the disease and may not be as involved as expected with care of the CF member (Frydman, 1979). The parents of a CF member may be fearful of the outcome of additional pregnancies, may have less time to spend together, and may have less energy to put into their relationship. They may be overprotective of

the CF member and have less time for their other children. Siblings may worry that they are carriers, feel guilty about being disease free, or guilty about having CF to a lesser degree than a sibling.

Although there is general agreement that family interaction and process is important in the care of the CF member (O'Grady, 1975; Davies & Addington, 1976; Kucia, 1977), few researchers have examined which characteristics or resources are most highly associated with family functioning. Rather, the emphasis has been on the physical and crisis aspects of the disease.

Earlier studies, which recorded characteristics and problems of individuals in CF families (Turk, 1964; Lawler, et al., 1966), derived information from very small samples in clinic settings, presenting a depressing picture of CF families (Vance, et al., 1980). Tropauer, et al., (1970), in a psychological study of twenty CF children and their mothers, concluded that anxiety, insecurity and emotional disturbances were evident and that the CF member and his/her parent were caught up in time, energy and money-consuming treatment plans. Lawler, et al., (1966) in a psychological and psychiatric study of eleven CF children reported that the majority of the parents presented "marked psychopathology and gross marital discord" (p. 1043) and that all the patients were preoccupied with death.

Frydman (1979) questioned such often-quoted impressionistic findings and reports which have been based on replies from biased samples and which have not been carried out with suitable controls. Generalizations from such small samples may lead to unfortunate stereotyping of CF families. Frydman also emphasized the importance of

providing comprehensive care to the CF family and of preventing secondary problems by identifying barriers to effective adjustment to CF. Steinhauer, et al., (1974) reported that CF families needed resources such as strength, stability and support, but did not elaborate on what these entailed.

More family authors are writing about family characteristics which are positive and helpful for family functioning. Although the family is reported as important in the care of the CF member and may have periods of stress (factors which are a part of family functioning), little information appears in the literature on the attributes of optimally functioning CF families.

Inside CF Family Boundaries

Focus on the internal aspect of CF families has tended to be on individual family members and their problems, or on different sub-systems of the family in which difficulties have arisen (Burton, 1974; O'Grady, et al., 1975; Bryce & Rodnan, 1978; Lewiston, 1980). The importance of the relationship dimensions which promote CF family functioning has not often been mentioned or emphasized. Mikkelson, et al., (1978) in a study of parents of 18 CF families however, found that respondents felt that their primary source of strength rested in their being able to share the work and worry with each other. Vance, et al., (1980), in a controlled study of the effects of nephrotic syndrome on 35 families, found that some families were strengthened and brought together by the shared experience of coping with a major illness.

Marital Dyad

Pratt (1976) stated that the consequences of a chronic illness on a family may be reflected in a decreased level of husband-wife communication, a loss of sharing and trust, and, hence, decreased marital integration. Other authors have reported that chronically unexpressed feelings typify the couple with a CF member (McCollum, 1975; Tropauer, et al., 1970), that the rate of breakdown in families with a severe chronic illness is high (Steinhauer, et al., 1974), and that there is an increased divorce and suicide rate in such families (Lawson, 1977).

The presence of a CF member in a family has also been reported to draw partners closer together (Travis, 1976), with a close and sharing marriage offering the greatest source of strength to parents of CF children (Mikkelson, et al., 1978). In evaluating the effect on the relationship of raising a child with CF, Begleiter (1976) found that the majority of couples (71%) felt that caring for an affected member had brought them closer together. McKeever (1981) reported that in a study of 10 fathers of chronically ill children, half of the fathers felt that coping with their child's illness had strengthened their marriage. The other half felt that the constant worry and tension associated with their child's illness had weakened their relationship with their wives. They went out less than once a month with their wives due to lack of energy or fear of leaving a sick child with a babysitter.

Some authors have expressed that marriages have been strained by an undercurrent of apprehension and stress created by the presence of

a chronically ill child, and that couples of such marriages spent less time together (Turk, 1964; Burton, 1974). Denning, et al., (1976) in a study of 104 families with CF children listed eight causes of marital stress: the treatment regime, the burden of care on one parent, fear of the death of the CF member, the financial burden, interference from relatives, the hereditary nature of CF, fear of pregnancy, and alcoholism.

It could be concluded that marriages in CF families are in jeopardy in light of such negative reports. Detailed exploration of marital satisfaction and strength in such marriages is sparse, with existing information coming mainly from mothers and from clinic families in stress related situations. There remains a conflict of opinion as to whether the amount of time and energy devoted by CF caregivers leads to emotional neglect and distancing of spouses (Patterson, 1980), or to bringing couples closer together (Begleiter, 1976; Travis, 1976).

Parental Dyad

Research on CF families has most often focussed on the information related to mothers. The mother has traditionally been the primary caregiver and the one on whom the burden of care for the CF member has fallen (Denning, et al., 1976). This situation easily lends itself to the mother becoming overly involved with and overly protective of the CF member, perhaps then having less time for the other family members. Such parent/child involvement may be regarded as somewhat undesirable for optimal family functioning. James & McIntyre

(1983) in discussing family therapy and the women's movement, however have argued that mother/child dyads and distant fathers should be seen as normal rather than "constituting an aberration in family functioning" (p. 127). They suggested that more consideration be given to psychodynamic and socio-political factors when dealing with families.

The proportion of women who are mothers and are employed has been steadily increasing in the Western World. Comeau, et al. (1980), however found in a study of 100 families with chronically ill children, including those with CF, that mothers with severely impaired children were most likely to remain at home in their caregiving role regardless of the financial situation.

According to McCollum (1975), fathers may feel excluded by the interdependent relationship of mother and child. Turk (1964) and Rosenstein (1970) concluded that fathers found ways to absent themselves from their families (working overtime, etc.) and were uninvolved in the daily care of their chronically ill members. McKeever (1981), however, found in a study of ten fathers, that fathers were deeply involved on a day-to-day basis but found interactions with their CF children, particularly their questions about the disease, difficult to handle.

There appears to be little consistent information in the literature on the parental dyad in CF families. Even less information appears to be available about the strengths or characteristics of parents which are associated with family functioning.

Siblings

Because of the time required for daily treatment of the CF family member, siblings may experience resentment, jealousy and insecurity. Tropauer, et al. (1970), reported that siblings of 20 families frequently deferred their wants and needs as the CF child became the focal point of family interactions. The brothers and sisters in CF families who also had the disease but to a lesser degree felt guilty for being healthier and some never knew their older CF siblings who had died.

Taylor (1980), in a study of the effect of chronic illness upon 25 well siblings, found that two-thirds of the group experienced feelings of isolation, felt excluded by the parent and ill child dyad and peripheral to the family at clinic visits. They felt ignored by health care providers and inadequate due to lack of feedback from parents. They felt deprived of adequate time and attention from parents to foster good relationships. Lack of touch and physical closeness were expressed, as well as feelings of guilt and inferiority. Although the overall impact was negative, there were some positive effects such as being able to assist family coping and feeling gratified with the results, assisting with the chores to relieve the ill sibling or parent, developing empathy, warmth and positive feelings as a result of living with ill siblings, developing a sensitive perception of how the parental relationship was affected by the illness, and receiving acceptance and praise for their involvement.

Vance, et al., (1980) studied 35 families with children with nephrotic syndrome and found that adolescent siblings showed lower

self-security, less social confidence than their peers, poorer academic achievement and were described by parents as having less favourable emotional health. The study revealed a picture of a sheltered, protected family environment, which suggested an enmeshed family system with closed boundaries and blurred generational boundaries.

Information in the CF literature on what happens inside families has focussed mainly on the effect of a CF member on individuals. Little has been written on the characteristics of relationship dimensions in the family and of the effect on family functioning.

Outside CF Family Boundaries

The nature of CF requires that families seek information, education and support from outside systems in order to provide optimal care on a daily basis at home. Permeability of boundaries permits this exchange. The time-consuming daily care, however, may reduce the ability of the family to maintain such outside networks (Pratt, 1976), and the family system may become closed at a time when network contact could be supportive.

Health Care Delivery System (HCDS)

The health care system consists of services which are designed to prevent disease and maintain health. The system is comprised of numerous disciplines, some of which are nursing, medicine, rehabilitation, mental health, pharmacology, laboratory services, education, religion, and nutrition (Hall & Weaver, 1977).

The Family - HCDS Interface

The management of the chronically ill child and his family requires the resources of a team of professionals (Steinhauer, et al., 1974). Epstein (1975) reviewed a philosophy of care which stated that the greater the number of specialists seeing an ill person, the more superior the care. She warned however, that a convergence of doctors, nurses, social workers, physiotherapists, inhalation therapists, vocational guidance workers, dietitians and others could overwhelm a family and leave them with the impression that they are "sick".

Mikkelson, et al., (1978) reported that mothers saw three main groups as important sources of support: concerned doctors who were honest and hopeful; social workers, especially around initial stages of dealing with diagnosis; and nurses, who were seen as important in the ongoing care by giving encouragement, emotional support and medical information. In McKeever's (1981) study, it was stated that fathers had less contact with health care professionals than mothers and that the fathers felt they received inadequate professional support or preparation about what to expect, particularly at the time of diagnosis.

With a home care treatment regime, the role of the family as a member of the health care delivery team is very important. Episodes of hospitalization are often crisis situations for CF families, in part because the boundary interface of the family and the HCDS may not be smooth. Steinhauer, et al., (1974), referred to behaviours such as parental criticism of hospital staff, parental over-involvement with the hospitalized child and overly demanding requests by parents of staff, as responses to anxiety and as displacement of family resentment

about having a seriously ill member. Mikkelson, et al., (1978) reported similar reactions such as parents expressing fear that staff would be too busy to give individual care and parents blaming themselves for being unable to prevent problems which resulted in the CF member being hospitalized. Some parents welcomed the opportunity to turn over the care to the experts, and to have temporary relief from such a responsibility. Some mothers who held unrealistic expectations of themselves perceived the need for help as a weakness, and were unable to ask for assistance (Mikkelsen, et al., 1978).

Mohr & Denning (1978), in providing care for approximately 200 families with one or more children with CF, reported that psychological consultation sought for supportive purposes focussed mainly on individuals such as parents, spouses of CF individuals, or adult CF individuals who were particularly dissatisfied with their general life patterns. Concern about the disease was usually a secondary factor. The way a psychological problem was perceived by the CF member and his family was a major determinant of the kind of psychological help they accepted. There was no emphasis or concern expressed in the report for systems such as the whole family unit, or for subsystems such as the marital system.

In 1977, Lawson stated that parents were an essential part of the health team and needed to be included in the planning and giving of treatment for the child. In a booklet "Cystic Fibrosis - Guidelines for Health Personnel" (1981), the team approach to care, while emphasizing the team members' roles in detail, however did not include the family's role in which the majority of daily ongoing care is given.

Health care involves both the physical and emotional elements of well-being. Outside family systems which are important, but which may be less obvious in providing support to families, are those of the church or ministerial system, and the school system.

Ministerial service. There are some references in the literature on the importance of religious values in families dealing with chronic illness. Settles (1980) reported that in families coping with chronically ill children, religiosity enhanced the parents' ability to meet the childrens' needs. In the Mikkelson study, religion also played an important role for parents. Minuchin, et al., (1975), however, cautioned that in rigid, overprotective families, a strong religious or ethical code may buttress and provide a rationale for avoiding conflict. Patterson (1981) stated that religion could be of assistance to many CF families. He suggested that the putting aside of traditional religious beliefs, may have compounded the self-reproachment observed in parents of CF children.

In the literature on CF families, authors do not elaborate upon the extent of the familys' involvement in religious or church activities. The place of the minister in the support system of these families is also not identified nor do the authors elaborate upon various family members' perception of religiosity or personal spiritual growth as a strength at various stages of development in the family life cycle or at the different stages of the disease. The spiritual or religious element, an area of strength and support, ought not to be overlooked (Fish & Shelly, 1978; Beavers, 1977; Patterson, 1981).

School. The school represents a natural extension of the family

for any child's development, both academically and socially. It is important to consider the behavioural and social effects of chronic illness on both the child and his or her school environment and on the family (Isaacs & McElroy, 1980). School absenteeism may be due to actual illness or the need to attend to regular medical progress checks and preventive care. Teachers may be reluctant to talk with parents about their chronically ill child because of their own fears and reactions concerning potentially fatal illness (Green, 1975). It is, therefore, important for parent-teacher contact to improve cooperation and understanding between family and school (Findlay, et al., 1969). Here, again, the authors of CF literature have placed little emphasis on family, but on the interaction between various individuals such as parent-teacher-child.

Extended family. The extended family includes individuals who are related to one another by blood or marriage. They include such individuals as parents, grandparents, brothers, sisters, aunts, uncles and in-laws.

At a time of increased mobility and long distances from families of origin, the availability of extended family to CF families is less than it was in the past. Mikkelson, et al., (1978) found that mothers who lacked the support of other family members or friends had a particularly difficult time coping with the stress of the disease. Frydman (1979) added that relatives were less likely to provide emotional support than tangible gifts. Croog, et al., (1972) in a study of 345 men with myocardial infarction found that the men received most help from their own families of origin, their siblings and

parents, followed next by friends and neighbours.

Relatives have been found to react with greater denial and vulnerability to the diagnosis of CF than parents (Meyerowitz & Kaplan, 1967). They may be called upon to give support at a time when they themselves need it. Extended family members' support may be tempered by the genetic aspect of the disease, and feelings of fear and blame may cause the family to withdraw (Begleiter, 1976; Gluckson & Denning, 1980; Thompson, 1980).

The literature on the role and importance of the extended family to CF families is scarce. Seen as an important resource in optimally functioning families, it is not clear how the extended family contributes to the functioning of CF families.

Recreation

The amount of time required to give CF care may often reduce or preclude time for leisure activities or for planning a vacation (Lawlor, 1977; McKeever, 1981). The degree to which CF families actively participate in outside recreation and sporting activities has not been extensively documented. Chinn (1979), however reported that such participation was associated with improved health and increased self-esteem of the afflicted family members. The importance of an active rather than a passive recreational orientation was stressed by Comeau, et al., (1980), in a study of 100 families with myelomeningocele and CF children. They found that families with an active recreational orientation were more likely to follow through on prescribed treatment regimes, and to maintain and sometimes improve the

level of health of the affected members.

Feedback in CF Families

In coping with the chronic illness of one or more members, families must respond to feedback originating from both inside and outside the family. Comeau, et al., (1980) found that families with a chronically ill child are likely to experience long term behavioural changes in family roles, rules, and patterns of interaction. The ability of a family to use a crisis or seemingly injurious experience as a means of growth is seen by some theorists as a strength (Otto, 1975). Organization and use of information by CF families who are functioning well however have not been documented.

In a study of 56 CF families, McCollum & Gibson (1970) described a process of four stages: prediagnostic; confrontational; long term adaptation; and terminal. Emphasis, however, was on the negative aspects of adaptation such as disorganization of the family, guilt and isolation. Similarly, Bruhn (1977) described the effects of chronic illness on families as disintegrative rather than integrative, disrupting the usual ways in which family members behave toward one another. Other authors (Turk, 1964; Grossman, 1975; Isaacs & McElroy, 1980) have described inter-personal problems such as overprotectiveness, marriage difficulties or scapegoating. They stated that where family members will not, or cannot, change roles and reallocate tasks, family breakdown becomes a real possibility, thus affecting the treatment regime (Davies & Addington, 1973; Bruhn, 1977). In the literature there is little or no discussion or

description of family characteristics, particularly of family strengths in the different stages of illness or family life cycle.

Optimal family functioning requires communication which will enable families to select information, decode it, use it and learn from the process. Positive communication skills enhance the family's ability to change its power structure, roles and relationship rules in response to new information (Olson, 1981). The need for CF families to respond to feedback from within and outside the family would seem to require high levels of family communication. Yet many authors who reported the lack of communication in CF families also emphasized the importance of parents' management of, and adjustment to, the disease (Turk, 1964; Meyerowitz & Kaplan, 1973; Steinhauer, et al., 1974; McCollum, 1975; Travis, 1976).

Although there is little supportive evidence, some authors suggest that the burden of caring for a chronically ill child may adversely affect the health of the parents (Settles, 1980). McKeever (1981) reported that, in CF families, fathers perceived mothers' health problems to include fatigue, anxiety, depression and migraine headaches. Fathers in CF families experienced chronic health problems, usually of a stress-related nature (Burton, 1975).

The duration and severity of the CF members' health must be considered in dealing with family functioning. Bruhn (1977) stated that severity of a chronic illness and a family's ability to adapt affects the outcome of the period of disequilibrium experienced by many such families. Boyle, et al., (1976), however, focussing on CF individuals and not families, reported that the functional level of

behaviour of the CF individual was not appear significantly related to either severity of illness or particular personality type. In a ten year longitudinal study of the functioning of 100 CF families, Sibinga & Friedman (1981) found that neither the severity of the disease nor its duration were related to parental coping patterns. It may be that other factors such as the health of the parents are more highly associated with optimal family functioning than the level of health of the CF member.

In a sample of 100 families taken from a wide range of sources, Moos & Moos (1976), using the Family Environment Scale (also used in this study and described in the methodology chapter), derived six styles of response to family feedback and pointed out how such styles of feedback response were linked to family outcome. The structure-oriented families represented eight percent of the sample. Characteristically they placed emphasis on structuring family activities, had explicit family rules and responsibilities, were strongly committed to the family and were inhibited in expressing anger and conflict. Nine percent of the families were expression-oriented, wherein members were encouraged to act openly and to express their feelings. There was, however, lack of clarity regarding rules and responsibility. The moral-religious oriented families made up eleven percent of the sample and emphasized ethical and religious issues and values. Independence-oriented families, twenty-four percent of the sample, tended to be assertive and self-sufficient, thought things out for themselves and made their own decisions. Nineteen percent of the families were achievement-oriented families and were characterized by

their strong emphasis on different types of activities in a competitive framework. They were interested in working hard and getting ahead in life. The sixth group of families were conflict-oriented with a high degree of conflictual interaction, emphasized by open expression of anger and aggression and a lack of concern, commitment, and mutual helpfulness and support in the family.

With the amount of contact CF families have with the health care delivery system and the amount of interpretation and application of information they are required to undertake in order to provide care for their CF members at home, the following characteristics are important for family functioning: permeability of boundaries, level of feedback and individual resources. There are no studies on CF families' styles of responding to feedback, nor on which styles might be most adaptive for them.

There has not been a tendency to view CF families as families from a systems perspective. Attention has been paid mainly to individuals in subsystems and associated areas of concern. There is also a sparcity of CF literature dealing with family functioning and intra-family relationships. Aside from somewhat negative speculation based on small clinic samples, who were likely in crisis, levels of family functioning and characteristics associated with CF family functioning have not been documented.

CHAPTER IV

METHODOLOGY

This study was part of a project entitled "Family Functioning in CF Families", conducted by Norah Keating and the author during the winter of 1981-82. The purpose and methodology were reviewed by the Ethical Review Committee of The Faculty of Home Economics of the University of Alberta and found to include ethical measures which safeguarded the privacy of both participating and non-participating families. This concern was especially important because the population studied was small and easily identified.

Data Collection

1. The proposal was submitted to the Executive of the Edmonton Chapter of the Canadian Cystic Fibrosis Foundation and permission to use their mailing list to seek participants for the project was requested (Appendix A.)
2. With this permission granted, request for participation was sent to those people on the mailing list of the CF Chapter by the secretary in the CF Chapter Office. Included with the request was a letter of endorsement and invitation from the Chapter President, two consent forms, and a stamped, addressed envelope for replies (Appendix B). The positive replies with phone numbers were forwarded to the investigators.

The letter of request informed potential participants of the reason for the project. The consent form emphasized that participation was voluntary, that the participants could withdraw at any time, and that responses would be held in confidence. The consent form included a question asking whether respondents had ever participated in previous research projects. This question was asked since the CF Clinic physician thought that the families had been exposed to too many research projects by students in areas such as nursing, nutrition, and medicine. Eighty-three percent of the women and 81 percent of the men had not participated in other research projects.

3. After the deadline for questionnaire return had passed, the CF Office Secretary placed a reminder in the CF Chapter Newsletter to return the questionnaires as soon as possible. All potential participants who had not replied to the mailed request were telephoned by the secretary.

4. The investigator telephoned the volunteer participants to arrange a suitable time and place for the interviews. During home visits, both partners worked on the questionnaires simultaneously, but separately. The demographic questionnaire, which was the only instrument requesting CF information, was completed last. In most cases, interviews were conducted in the home of the participants. Where personal interviews were not feasible because of distance or weather, the questionnaires and the instructions were forwarded by mail with an addressed, stamped return envelope. Availability of the investigator by

telephone was ensured. When the questionnaires were not returned, a follow-up phone call was made by the investigator. Such calls resulted in the return of the completed forms.

5. Responses were identified by a code number protecting participants' identity.

Sample Selection

The sample was drawn from eighty-two families in Northern Alberta with one or more diagnosed CF members and whose names appeared on the mailing list of the Edmonton Chapter of the Canadian CF Foundation. The sample consisted of those families in which one or both spouses volunteered to participate by signing and returning consent forms.

Of the eighty-two families contacted, 33 were willing to participate (40%), 11 sent back negative replies and 38 did not reply.

Instrumentation

Four questionnaires were used. Three were established and published instruments: the Family Functioning Index (FFI); the Family Environment Scale (FES); and the Family Inventory of Resources for Management (FIRM). The General Information questionnaire was designed and pretested by the researchers.

Family Functioning Index (FFI)

The FFI (Appendix C) is a screening instrument, developed by Pless and Satterwhite (1973) as a simple, easily administered and easily scored test to assess the functioning of families with a

chronically ill child. The FFI focuses on relationships between family members. It was designed to measure the functioning and the strength of relationships and the life style of the family as a whole (Strauss, 1978). The principle components with which it deals are intra-family relationships: cohesiveness, decision-making, marital satisfaction, frequency of disagreements, communications, weekends together, problem-solving and a general assessment of happiness and closeness of the family unit. The FFI is comprised of 17 questions. Each response is assigned a score, the sum of which range from 0-39, with the higher scores indicating a more desirable and healthier level of functioning. The total score on the FFI was used in this study as a global measure of family functioning.

Reliability of the FFI includes a correlation of .72 between the scores of husbands and wives, obtained independently (Pless & Satterwhite, 1973). For test-retest reliability, a correlation of +.83 (p .001) was obtained for the whole instrument over a five year period (Satterwhite, et al., 1976).

Validity studies were done by correlating FFI scores of mothers with ratings by social workers and non-professional counsellors who knew the 65 families. The mothers' scores were correlated with the ratings of the workers, $r = .39$, p .001 (Pless & Satterwhite, 1973).

FFI Revisions. The FFI as a family functioning instrument has generally been administered only to parents. The original scale was apparently intended for use only with women as all references to spouse are "husband." Because the present study was to include individuals who were not in intact marriages, the FFI was modified slightly to

include respondents whose significant other was not a spouse. The word "husband" was changed to "partner," making the instrument more relevant for use by both men and women. Scoring was not affected by these changes.

The instrument was obtained in microfiche form from the National Auxiliary Publication Service (NAPS-II), New York, and was transcribed into a usable format.

Family Environment Scale (FES, FORM R)

The FES (Appendix D) is a 90 item true-false instrument developed by Rudolph H. Moos in 1974 to assess the social climate of all types of families.

> It focusses on the measurement and description of the interpersonal relationships among family members, on the directions of personal growth which are emphasized in the family, and on the basic organizational structure of the family (Moos, Insel, Humphrey, p. 3).

The scale can be used by family members themselves or by observers such as psychotherapists and marriage counsellors. The scale can also be used to compare and contrast the social climates of different families, to study families over time, to evaluate change in family social environments related to intervention programs and to enhance the richness of clinical case descriptions (Strauss & Brown, 1978).

The FES is comprised of ten subscales which fall into three dimensions.

Relationship Dimension. Subscales one to three assess the extent to which family members feel that they belong to, and are proud of

their family, the extent of open expression within the family, and the degree to which conflict is characteristic in the family.

1. Cohesion. This subscale measures the extent to which family members are concerned with and committed to the family. It includes items designed to reflect enthusiasm, support and constructive activity.

2. Expressiveness. This subscale measures the extent to which family members are allowed and encouraged to act openly and to express their feelings directly.

3. Conflict. This subscale assesses the extent to which open expression of anger and aggression and generally conflictual interactions are characteristic of the family.

Personal Development or Personal Growth Dimension. Subscales four to eight measure the emphasis within the family on certain developmental processes that may be fostered by family living.

4. Independence. This subscale measures the family's emphasis on autonomy and family members doing things on their own, and assesses the extent to which family members are encouraged to be self-sufficient and to make their own decisions, including items related to personal development and growth.

5. Achievement Orientation. This subscale measures the family's emphasis on academic and competitive concerns and assesses the emphasis on achievement, getting ahead in life, and setting high goals.

6. Intellectual Cultural Orientation. This subscale assesses the family's emphasis on intellectual and cultural activities, such

as going to lectures, plays and concerts; reading books; playing musical instruments; and engaging in artistic or craft-type activities.

7. Active Recreational Orientation. This subscale assesses the extent to which family members are encouraged to have hobbies, to be involved in a variety of activities outside work or school, and to have diverse interests.

8. Moral Religious Emphasis. This subscale measures the extent to which the family emphasizes and discusses ethical and religious issues and values.

System Maintenance Dimension. The last two subscales are system-oriented in that they obtain information about the structure or organization within the family and the degree of control usually exerted by family members vis-a-vis each other.

9. Organization. This subscale measures the family's emphasis on variables such as neatness, structuring family activities, financial planning, and punctuality.

10. Control. This subscale assesses the extent to which the family functions by relatively strict "rules and regulations" or procedures (Moos, Insel, Humphrey, 1974, p. 4).

Each subscale is made up of nine items on the test with a potential score between 0 and 9. The total scores for each subscale were used in this study.

The FES was used because it gives a profile of family environment through an exploration of areas of family functioning such as problem-solving, communication, affective responsiveness, roles,

affective involvement and behavioural control.

Internal consistency scores ranging from .64 to .79 have been reported for the ten subscales. Test-retest reliability since have ranged from .68 (independence) to .86 (cohesion) (Moos, 1976). Comparison made between 42 clinic families and 42 matched normal families indicated the difference between the two was consistent with expectations and provided initial support for the construct validity of FES (Moos, Insel, Humphrey, 1974).

Family Inventory of Resources for Management - FIRM

FIRM (Appendix E.) was developed by McCubbin, Comeau and Harkins in 1981 using a population experiencing chronic illness, to assess the family's repertoire of resources in three major areas: (a) personal resources, (b) the family system, and (c) social support. Perceived family resources are measured by four subscales. The internal reliability for each has been reported to be .89 (Cronbach's alpha).

The four scales are:

Family Strengths I: Esteem and Communication. This subscale measures personal, family system and social support resources in six areas:

1. family esteem (respect from friends, relatives, co-workers, and among family members),
2. communication (sharing feelings, discussing decisions),
3. mutual assistance (helping each other and relatives),
4. optimism,
5. problem solving ability, and

6. encouragement of autonomy among family members.

The score on this subscale is the sum of 15 items on the instrument. The Internal Reliability has been reported as .85 (Cronbach's alpha).

Family Strengths II: Mastery and Health. This subscale includes items that reflect personal, family system, and social support resources along three dimensions:

1. sense of mastery over family events and outcomes (fate control, flexibility, managerial abilities),
2. family mutuality (emotional support, togetherness, cooperation), and
3. physical and emotional health.

The score of this subscale is the sum of 20 items on the instrument. The Internal Reliability has been reported to be .85 (Cronbach's alpha).

Extended Family Social Support. This subscale contains items which indicate the mutual help and support given to and received from relatives. The score is the sum of four items on the instrument. The Internal Reliability has been reported to be .62 (Cronbach's alpha).

Financial Well-Being. This subscale reflects the family's perceived financial efficacy:

1. ability to meet financial commitments,
2. adequacy of financial reserves,
3. ability to help others (relatives, the needy), and
4. optimism about the family's financial future (adequacy of insurance, employment benefits, retirement income, earning power, and the family's financial progress).

The Internal Reliability has been reported to be .85 (Cronbach's alpha)

(McCubbin & Patterson, 1981, p. 62).

Two other variables included in FIRM, but which are not included in this study, are sources of financial support and social desirability. It is important to understand along with family functioning which resources are salient to families in order to provide optimal care. FIRM provides a means to examine these resources on several levels; individual, within family, and outside family sources.

General Information (Demographic) Questionnaire

The demographic questionnaire (Appendix F) was designed to gather information about the respondents and their family situation in several areas. Personal information included age, sex, marital status, country of birth, type of occupation, educational level, employment status, income level, and health status. Family information included number of children, birth order, ages of children, number of live children, number of deceased children, home ownership and size, and number of housing moves made in the last two years. CF information had to do with the number of CF children, deaths due to CF, number of years living with CF, severity of CF, amount of hospitalization due to CF, and cooperation of CF person with treatment, the school, the primary care giver, and other help. The last page of the questionnaire provided participants with an opportunity to voice particular concerns or to make further comments.

Information was sought about the health care services and other outside resources families used, which services and resources were used the most, and which gave the most emotional support.

Analysis

In this study tests of correlations were conducted between the FFI and the family. Variables are listed in Appendix G. The inferential associational statistical test Pearson product-moment (product-moment r) was chosen for analysis. This test permits investigation of the extent to which variation in one factor corresponds with variations in one or more other factors.

Tests of correlation are appropriate where variables are complex and/or do not lend themselves to the experimental method of controlled manipulation. A correlation statistical test permits the measurement of several variables and their interrelationships simultaneously and the degree of such relationships. A product-moment r may be used as a profile measure where a researcher looks for the association between specific characteristics or complexes of characteristics. The degree of relationship can vary from -1.0 to +1.0. The magnitude of the relationship is indicated by the absolute value of the correlation coefficient. The (+, -) sign of a coefficent only indicates the direction of the relationship and a coefficient of 0.0 indicates no correlation between two variables (Kerlinger, 1973). In this study alpha was set at .05, a level commonly used in the social sciences.

Correlational statistics do have limitations. They only identify the relationships which exist and do not necessarily identify cause-and-effect relationships (Isaac & Michael, 1979; Hinkle, et al., 1979).

CHAPTER V

FINDINGS

The description of the CF families and their Family Functioning Index scores are presented first, followed by the findings of the Family Environmental Scale, the Family Inventory of Resources for Management and the contact of the families with the health care system. The correlation scores between the Family Functioning Index scores and individuals, within and outside family variables are then presented.

Description of the Families

Age. Women's ages ranged from 23 to 63 years, with a mean of 37 years; and the men from 26 to 68 years, the mean being 42 years.

Marital Status. Of the 33 families participating in the study, both husbands and wives in 26 families completed the interviews; in 3 families, only wives completed the interviews. The four remaining families were headed by women who were separated or divorced and they were not included in the study as only families with both parents present were included. There were 29 families with intact marriages. The length of marriage ranged from one to 39 years with a mean of 16 years.

Children. The families had an average of 2 children with a range of one to three. The mean age of the children was 26 years with a range of a few months to 31 years. There were 32 CF children (see Table 1). Their ages ranged from a few months to 28 years with the

Table 1

Number of Live CF Children, Their Ages and Birth Order

Age Range	Birth Order and Gender						
	#1 (n=11)		#2 (n=13)		#3 (n=8)		
	Male	Female	Male	Female	Male	Female	Total
0 - 5 years	2	0	3	2	1	0	8
6 - 12 years	5	0	1	4	0	2	12
13 - 18 years	3	0	2	0	2	1	8
Over 18 years	1	0	1	0	2	1	4
Total	11	0	7	6	5	3	32

mean age of 13 years. Twenty-one children were male and 11 were female. These families had had eight deaths attributed to CF. The ages of the children who had died of CF ranged from birth to 16 years, with a mean age of eight years. Only one of the eight children who died was a male.

Place of Birth. Eighty-four percent of the sample were Canadian born, and the others were born in the British Isles, Europe, Asia and Africa.

Education. More than one half of the women (66%) had some post-secondary education, 31 percent had completed high school and 3 percent had less than 8 years in school. The men had, on the average, slightly less education than the women. Forty-six percent had some post-secondary education and 54 percent had completed high school (see Table 2).

Employment. Fifty-nine percent of the women were homemakers with 28 percent in clerical or teaching occupations. The remaining 17 percent were in caretaking, farming, management or paramedical jobs (see Table 3). Of the women employed, 62 percent had full-time jobs, and 38 percent had part-time jobs (see Table 4).

Fifty-eight percent of the men were in occupations involving production-fabrication, machinery, transportation and farming. The remaining 35 percent were employed in other areas such as management, law, teaching and sales (see Table 3). The men were all employed full-time except for one who had retired. One did not respond to the item on the questionnaire (see Table 4).

Income. The total annual family income ranged from $5,000.00 to $31,000.00 and over, with a mode of $31,000.00 and over (see Table 5).

Table 2

Educational Level

	8 years	9-12 years	some university	Degree
Women n=29	3%	31%	41%	25%
Men n=26	15%	39%	15%	31%

Table 3

Type of Occupation of Men and Women

Occupation	Women (n=29)	Men (n=26)
Homemaker	59%	-
Law	-	8%
Manager	3%	15%
Teacher	11%	8%
Med-health	3%	-
Clerical	18%	-
Sales	-	4%
Farm	3%	15%
Machines	-	8%
Production	-	23%
Transportation	-	11%
Caretaker	3%	-
No Response	-	4%

Table 4

Employment Status of Men and Women

Employment Status	Women (n=29)	Men (n=26)
Full-time	28%	92%
Part-Time	17%	-
Not Employed	55%	8%

Table 5

Total Annual Incomes of 26 Couples (Respondents) and of Men and of Women Separately

Annual Income Ranges	Couples	Women (n=29)	Men (n=26)
Under $5,000	-	59%	8%
6,000 - 10,000	4%	7%	-
11,000 - 15,000	-	14%	-
16,000 - 20,000	4%	-	8%
21,000 - 25,000	4%	3%	8%
26,000 - 30,000	12%	-	23%
Over 31,000	62%	10%	38%
No Response	14%	7%	15%

Health. All 29 women reported being in good physical and mental health. Twenty-one reported that they were in excellent physical health, 8 in good physical health, 17 in excellent mental health and 12 in good mental health.

Of the 26 men, nine reported being in excellent physical health and 17 men indicated that they were in good physical health. Seventeen reported being in excellent mental health, 6 in good mental health and 2 in poor mental health (see Table 6).

Primary Care Giver. The primary care giver was the person who was responsible for giving the actual CF treatment required in daily care of the individual with Cystic Fibrosis. The majority of the sample perceived the mother as the primary care giver. Twenty-seven percent of the men saw themselves as sharing the caregiving: whereas, only 17 percent of the women perceived that the caregiving was shared (see Table 7). Only a small number of the women indicated that they had other help with caregiving. This help was provided by the fathers and other children in the family.

Effect of CF on Family Members. The majority of men and women reported that the effect of a CF member upon the marriage relationship was positive (see Table 8). The effect of the presence of a CF member in the household on the lives of their other children was reported as positive by sixty-four percent of the respondents (see Table 9).

Mobility. Over the last two years, 65 percent of the sample had lived in the same house, 15 percent had moved once or twice, and 21 percent had moved 3 or 4 times.

Distance from Services. Seventy-five percent of the sample lived

Table 6

Ratings by Men (n=26) and Women (n=29) of Their Present Mental and Physical Health Status

Health Status	Women n=29	Men n=26
Mental Health		
Excellent	59%	69%
Good	41%	23%
Poor	-	8%
Physical Health		
Excellent	72%	35%
Good	28%	65%
Poor	-	-

Table 7

Primary Care Givers

	Shared (Mother & Father)	Mother (Main)	Father (Main)	CF does own
Women n=29	17%	77%	3%	3%
Men n=26	27%	69%	-	4%

Table 8

Men's and Women's Perception of the Effect of a CF Member Upon the Relationships with Partner

Effect	Women n=29	Men n=26
Highly positive	45%	54%
Somewhat positive	38%	34%
Somewhat negative	7%	8%
Highly negative	3%	-
No response	7%	3%

Table 9

Ratings of Both Men and Women of the Effect of the Presence of a CF Member in the Household on the Lives of Their Other Children

Effect	Respondents
Highly positive	35%
Somewhat positive	29%
Somewhat negative	20%
Highly negative	2%
Not applicable	14%

n=55

within 50 miles of the CF Clinic in Edmonton. Fifteen percent lived from 50 to 200 miles away from Edmonton, and 12 percent were more than 200 miles away from Edmonton.

Home Ownership. Ninety-eight percent of the sample owned their own homes.

Family Environment Scale (FES).

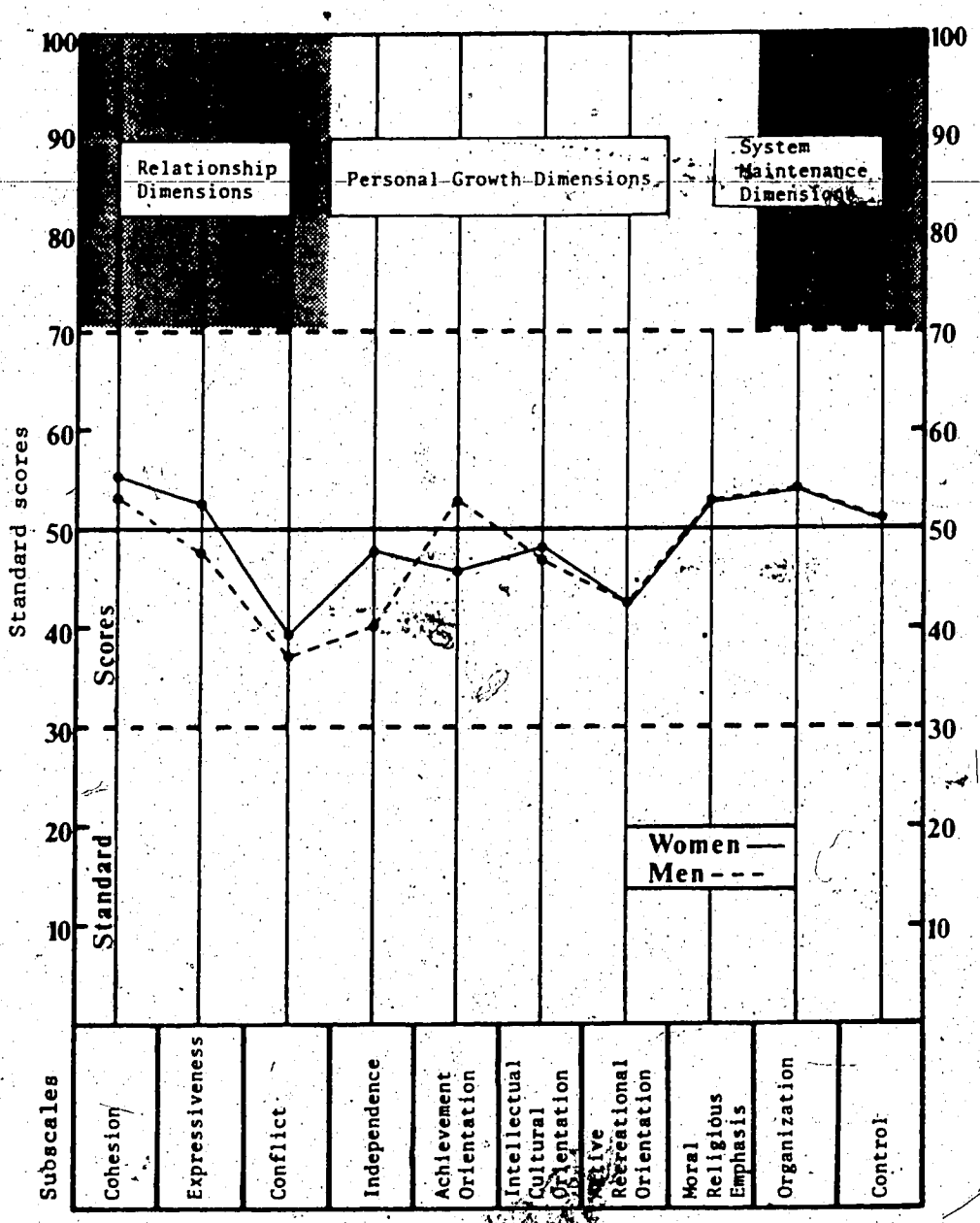
The results of the FES are represented in Figure 5. Raw scores were converted to standard score equivalents. Authors of the instrument (Moos, Insel & Humphrey, 1974) used the standard score of 50 for ease in graphing and this score on the profile is referred to as the median in this report.

Relationship Dimension. In the relationship dimension, women's scores were slightly higher than those of the men. Women scored well above the median on the cohesion subscale, slightly above the median on the expressiveness subscale and substantially below the median on the conflict subscale.

Men, who scored slightly above the median on the cohesion subscale, scored slightly below the median on the expressiveness subscale and well below the median on the conflict subscale.

Personal Growth Dimensions. Women were below the median on the three subscales of independence, achievement orientation, intellectual-cultural orientation and considerably below the median on the active recreation orientation subscale. They were, however, somewhat above the median on the moral-religious emphasis subscale.

Men were well below the median on the independence subscale but



*Subscales which were correlated with the Family Functioning Index scores

Figure 5: Family Environment Scale Profiles for Men and Women (n=55)

scored above the median on the achievement-orientation subscale. Scores for men on the intellectual-cultural orientation subscale were slightly below the median and then coincided with the women's scores on the active-recreation orientation and moral-religious subscales.

System Maintenance Dimensions. Both men's and women's scores were above the median on the organization subscale and the control subscale.

Family Inventory of Resources for Management (FIRM)

The ranges of scores and the means of the four resource subscales for men and women are shown in Figure 6, with the standardized means for the instrument. Scores to the left of the standard deviation line indicate a lack or depletion of resources in that area. Scores to the right of the line indicate a better-than-average supply of resources upon which a family may draw. Scores within the demarcated line indicate a moderate resource level in that area. Mean scores are indicated on all the lines by a small vertical slash.

On the esteem and communication subscale, there was a broader range of scores for men. They ranged from better than average resources to a lack or depletion of resources, while the women's scores ranged from average to above-average. The mean for the men and women was slightly higher than the standard mean for the instrument.

On the mastery and health subscale, there was a broad range of scores for women, which was slightly less so for men. The mean for men and for women was slightly above the standard mean.

On the extended family social support subscale, the means for men

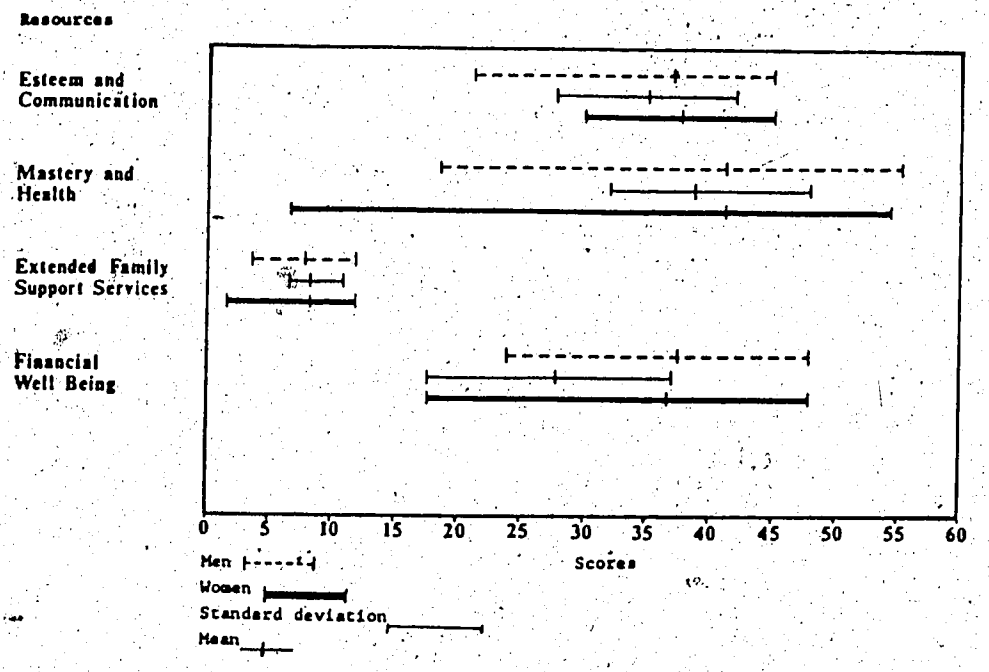


Figure 6: Family Inventory of Resources for Management: Means and Ranges of Scores for Men (n=26) and Women (n=20)

and women were slightly below the standard mean for the instrument. The range of scores found for women was slightly broader than for men although the top score was the same as that found for men.

On the financial well-being scale, the means for men and women were well above the standard mean for the instrument. A wider range of scores was found for women, the majority of whom were not employed outside the home and whose income did not include that of their spouses.

Contact with the Health Care System

The pattern of contact with the health care system in some instances had been different for men and women, both of whom had contacted the health care personnel in the past year (see Table 10). Women had more contact with the health care delivery system than men and contacted the CF Clinic doctor, the family doctor, and the nurse most often. This is understandable as the women provided much of the treatment in the home-based care program of the CF member. With the addition of the minister, these contacts also gave the women their main support, findings which are similar to those of Mikkelson, et al., (1978).

Men indicated that they had contact with the same personnel as the women, the most contact being with the CF Clinic doctor, the family doctor, and the pharmacist. Men's pattern of use of health care personnel was different than that of women, in keeping with their role as family supporter and assistant with CF caregiving.

Women's greater involvement with direct care to their CF member brought them in more frequent contact with certain services of the

Table 10

Contact and Support of Health Care Delivery Personnel by Men and Women During the Previous 12 Months

Percentage of Respondents' Contact with Health Care Personnel		Person Most Frequently Contacted	Person Giving Main Support
Women (n=26)			
CF Clinic doctor	(100%)	CF Clinic doctor	CF Clinic doctor
Family doctor	(77%)	Family doctor	Nurse
Dietician	(69%)	Nurse	Family doctor
Pharmacist	(65%)		
Nurse	(62%)		
School Teacher	(50%)		
Physiotherapist	(38%)		
Inhalation Therapist	(27%)		
Minister	(27%)		
Social Worker	(19%)		
Psychologist	(12%)		
Family Counsellor	(4%)		
Genetic Counsellor	(0%)		
Men (n=19)			
CF Clinic doctor	(89%)	CF Clinic doctor	CF Clinic doctor
Family doctor	(68%)	Family doctor	Nurse
Pharmacist	(68%)	Pharmacist	Minister
School Teacher	(53%)		
Dietician	(47%)		
Physiotherapist	(32%)		
Nurse	(32%)		
Minister	(32%)		
Social Worker	(16%)		
Psychologist	(11%)		
Inhalation Therapist	(11%)		
Family Counsellor	(0%)		
Genetic Counsellor	(0%)		

health care delivery system, in particular, the CF clinic staff and the family doctor who coordinated the CF member's care and referral to other services. As reported in previous studies of CF families (Rosenstein, 1970; McCollum, 1975; McKeever, 1981), men in this study had less contact than women with the health care delivery system. However, they provided indirect care to their CF member and to their spouse by picking up prescriptions, seeing teachers, working on fund-raising projects and sharing caregiving responsibilities.

Men who had no contact with the health care systems indicated either that spouses handled all the contacting or that their CF member was old enough to make all the necessary contacts themselves. Women who had no contact with the health care system indicated that the CF member did their own care. Respondents did not indicate that any of the services were unavailable and did not add any further services that may not have been listed.

No contact had been made by anyone in the sample with a genetic counsellor. This does not mean that such counselling had not occurred perhaps through other disciplines, but that the genetic counselling service had not been tapped during the last twelve months. It is not a service which must be used frequently by CF members and may have been sought only once by concerned parents, siblings, and concerned relatives of CF individuals. Hence, it is not surprising that this sample had not sought such service in the particular twelve month period examined.

Complementary to the physical component of well-being are the emotional and spiritual components. These latter aspects of well-being

tend to be addressed by the ministerial and school systems which are therefore included in this section.

School

Fifty percent or more of the men and women contacted the school teacher as a resource and 93 percent of the respondents who had children in school indicated that the schools were cooperative regarding management of the child's CF care (see Table 11).

The contact between the school and parents appeared to be congenial even though parents expressed concerns about the CF child's adjustment to starting school (see Appendix H). The child's progress in school may depend upon the number of absences due to illness or keeping of medical appointments, the success of accomodating the treatment regime which may have to be extended into the school setting, and the reaction of teachers and other children to the disease. Not only must the school understand the CF member as an individual, it must also know and understand the family unit from which the member comes. This has been stressed by Isaacs & McElroy (1980).

Ministerial Services

For both men and women, the minister was seen as one of the main sources of support. There was, however, no indication of whether contact with the minister was an ongoing part of family life, or if it was made only during times of stress or crisis by an individual or a group of family members, or if the frequency of contact was at certain stages of the disease or family life cycle.

Table 11

Rating by Men and Women with School Age Children of School's Cooperation Regarding Childrens' CF

		Respondents	
		Women n=14	Men n=12
School Cooperation	Cooperative	57	67
	Somewhat Cooperative	36	25
	Somewhat Uncooperative	-	8
	Uncooperative	-	

Hospitalization

During the previous twelve months, the total number of days of hospitalization and the range of days hospitalized was greatest for the second born group of children. In this group, in which males and females are close in numbers, the reported range of severity of the disease (on a scale that ranged from slight to severe) was mild to severe, perhaps resulting in the increased days of hospitalization (see Table 12).

Family Functioning Index

The Family Functioning Index (FFI) scores ranged from 12 to 39. The average score for the total group was 30; the mode was 36 (see Figure 7). Sixty-seven percent of the total sample had scores of 30 or greater. Based on a median split which has been used frequently in other studies (Phares, 1965; Levinson, 1973), high functioning families would fall between the scores of 32 and 39.

For women, the scores ranged from 12 to 39 with a mean of 30 and a mode of 36. Seventy-two percent of the women had scores of 30 or greater. Men's scores ranged from 13 to 39 with a mean of 30. The scores were bimodel: 30 and 31 (see Figure 8).

Correlation Scores

The correlations between the FFI and the boundary, feedback, and individual resource variables are presented in Table 13.

Table 12

Birth Order, Severity of Condition and Hospitalization (in Previous 12 Months) of CF Males and CF Females

Sex, Severity & Hospitalization	Birth Order 1	2	3	4
Males	11	7	3	0
Females	0	6	5	0
Severity of Condition	sl.-mod. [severe 0]	mild-sev. [slight 0]	mild-sev. [slight 0]	N/A
Total days of hospitalization	46	319	212	N/A
Range: Days of Hospitalization	0-36	0-105	0-60	N/A
Average: Days of hospitalization	4 days	25 days	27 days	N/A

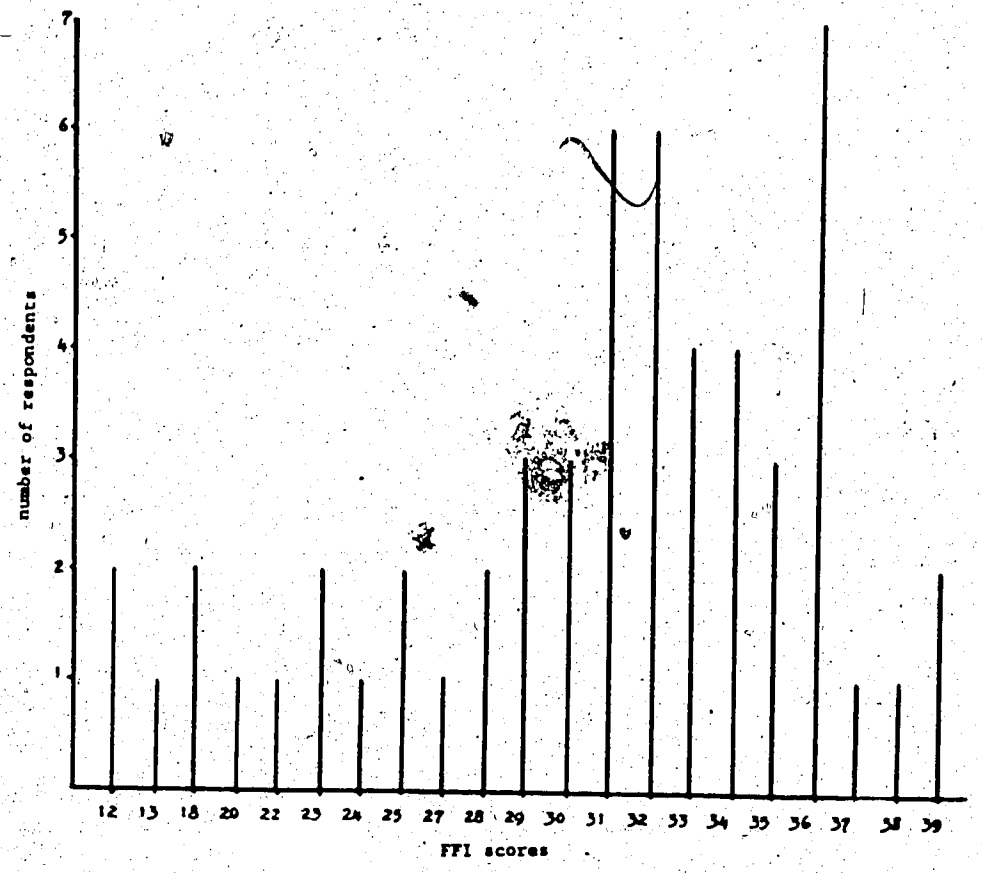


Figure 7: Family Functioning Index (FFI) Scores for the Total Sample (n=55)

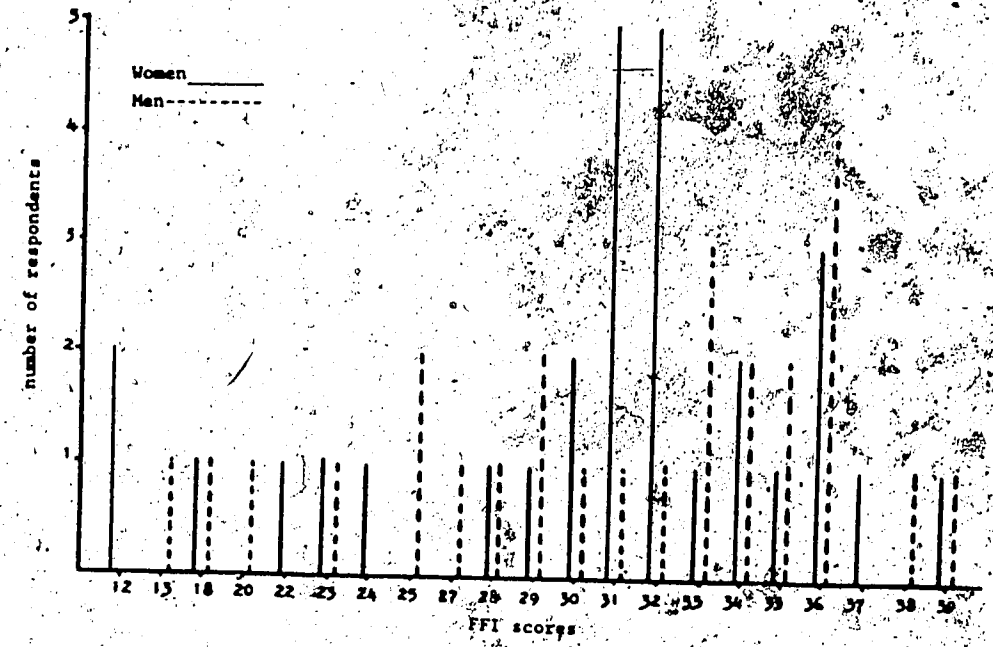


Figure 8: Family Functioning Index (FFI) Scores for Men (n=26) and Women (n=29)

Table 13

Correlation Scores Between Family Functioning Index (FFI) and Boundary, Individual and Feedback Resource Variables

Variables	Sex	
	Women r	Men r
Boundary (Within Family)		
FFI & Cohesion (FES)	.53**	.71**
FFI & Conflict (FES)	-.50**	-.54**
FFI & Effect of CF on Marital Relationship	.45**	.06
Boundary (Outside Family)		
FFI & Extended Family Support (FIRM)	.03	.40*
Individual		
FFI & Physical Health of Respondent	.45**	.14
FFI & Mental Health of Respondent	.43*	.21
FFI & Education	.42*	.37*
FFI & Financial Well-being (FIRM)	.51**	.48**
FFI & Achievement Orientation (FES)	-.41**	-.55**
FFI & Active Recreation Orientation (FES)	.38**	.10
Feedback		
FFI & Organization (FES)	.62**	.62**
FFI & Mastery and Health (FIRM)	.80**	.61**
FFI & Esteem and Communication (FIRM)	.40*	.72**
FFI & Number of Children with CF	-.43*	-.35*

* Significant at or beyond .05 level
** Significant at or beyond .01 level

Boundaries Within the Family

There was a high positive correlation for men and a moderately positive correlation for women, both significant at the .01 level, between cohesion and the FFI. The correlation between conflict and the FFI was moderately negative for both men and women ($p = .01$). There was a low positive correlation between the effect of a CF member on the marital relationship and the FFI for women only ($p = .01$) (see Table 13).

Boundaries Outside the Family

The only outside of the family variable which correlated with the FFI was that of extended family support. A low positive correlation at the .01 level was found for the men only.

Other resources outside of the family such as various members of the health care delivery system, the school, the church, and recreation did not significantly correlate with level of family functioning.

Individual

For women only, there was a low positive correlation between physical health and the FFI and active recreation orientation and the FFI at the .01 level, as well as between mental health and the FFI at the .05 level. A low positive correlation occurred between education and the FFI for men and women at the .05 level while a moderate positive correlation occurred between financial well-being and the FFI for both at the .01 level. A negative correlation, which was low for women and moderate for men, occurred between achievement orientation

and the FFI at the .01 level for both.

Feedback

There was a moderate positive correlation between organization and the FFI for both men and women at the .01 level. A positive correlation which was high for women and moderate for men occurred between mastery and health and the FFI at the .01 level. There was a low positive correlation for women between esteem and communication and the FFI at the .05 level while for men there was a high positive correlation at the .01 level. There was a low negative correlation for men and women between the number of CF children in the family and the FFI. However, given the size of the sample, these correlations could be important despite the fact that they were low and in this small group.

Summary

Not only did the data analysis indicate a relationship between family functioning in the areas of boundary, feedback and individual resources, they also indicated that, in CF families, individual resources of women were more likely to be associated with family functioning than those of the men (see Figure 9).

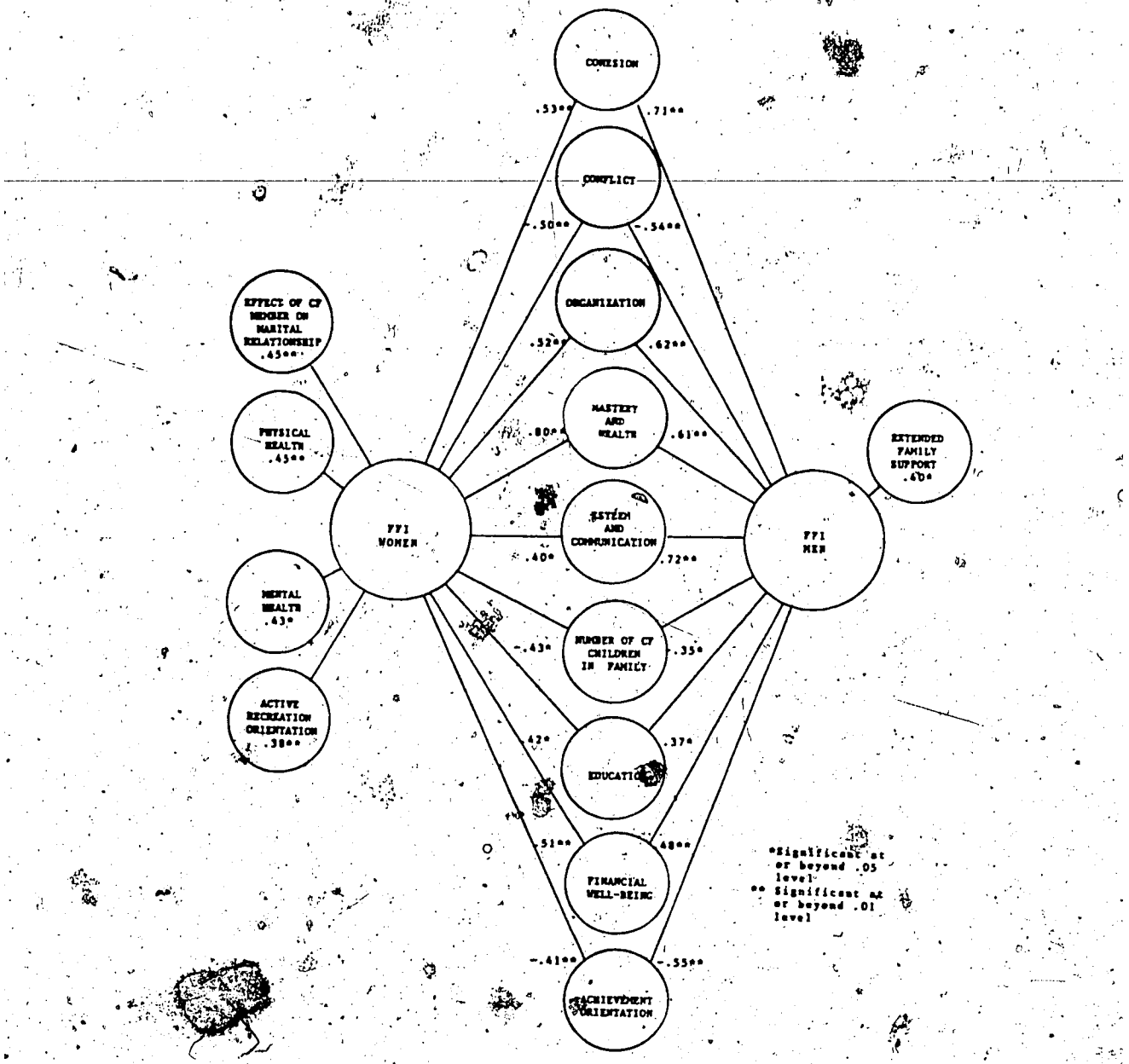


Figure 9: Relationships Between Boundary, Feedback and Individual Resource Variables and the FFI Scores for Men and Women

CHAPTER VI

DISCUSSION, CONCLUSIONS AND IMPLICATIONS

The first three research questions (see page 3) were descriptive questions and were addressed in the previous chapter. The focus here is on the discussion and the implications of the correlation findings.

Discussion

In the following discussion, variables which were correlated with the FFI will be discussed under the systems concepts of boundaries (inside and outside the family), feedback and individual resources. Certain variables which were not correlated with the FFI will also be drawn into the discussion of characteristics of CF families in this study.

Within Family Boundaries

The three variables which correlate with the FFI were cohesion, conflict and the effect of a CF member on the marital relationship.

Cohesion. Family researchers and theorists previously cited suggest that amongst the features of optimally functioning families include the ability to get along with and support each other, the feeling of togetherness and mutuality, and the existence of clear generational boundaries. In this study, there was a correlation between cohesion and the FFI for both men and women, supporting the findings of Lewis, et al., (1976), Stinnett (1980), and Fisher, et al.,

(1982) of emotional bonding of family members in optimally functioning families. Family closeness received higher than average emphasis reflected by the respondents positive responses to items such as "Family members really help and support one another", "There is a feeling of togetherness in our family", "We really get along well with each other". Family closeness was important for the men and women in this study.

Cohesiveness may be slightly different for the women in the study families than for the men. Since the mothers, as primary caregivers, have much more contact with the CF member, it may be hard for them not to have a relatively enmeshed relationship with the CF member. It may be that the fathers are less enmeshed with the CF member because they give less direct care. Nonetheless, the fathers in this study saw themselves as interested and involved. This finding supports that of McKeever (1981) who found that fathers were involved with their CF family member.

Further evidence of cohesiveness was evident in the positive effect of a CF member on the relationship with one's partner and in the importance placed on communication as a resource. The correlation between cohesiveness and the FFI also supports the findings on the importance of family unity (Fisher, et al., 1982; Vance, et al., 1980).

Conflict. Members of optimally functioning families are reported in the literature as being sensitive to feeling states, allowing conflict to arise and then resolving it through negotiation (Beavers, 1977). Conflict was negatively correlated with the FFI for both men and women in this study. Conflict may represent lack of concern or

distance and may add stress and tension to a situation in which resources of CF family members may already be taxed. Respondents in this study, however, were close and caring, and placed lower than average emphasis on conflict by responding positively to items such as "Family members rarely become openly angry", "If there is a disagreement in our family, we try to smooth things over and keep the peace", and "In our family, we believe that you don't get anywhere by raising your voice". In these CF families, optimal family functioning is more likely to be enhanced when there is a minimum of open expression of anger and some resolution of conflict.

Marital Relationship. A strong marital relationship has been cited as a characteristic of optimally functioning families. However, in some CF literature, marital stress was cited as a result of having a CF member in the family. Although both men and women saw the effect of a CF member on the marital relationship as positive, it was only for women that there was a positive correlation occurred between the effect of the CF member on the relationship and the FFI. Women may see themselves as fulfilling important tasks in their traditional role of mother. In particular, as the CF caregiver in the home, they may receive positive reinforcement from outside contacts, such as health care system, for the job they are doing with their child. Such reinforcement may reduce the woman's need for additional reinforcement from her husband, thus serving to enhance the marital relationship and optimal family functioning.

As women focus more of their energy on traditional parenting roles, men in traditional roles may be confronted with the enmeshment

of their wives and CF child, in much the same way men in non-CF families might. Little may change for men outside the home, where they may receive much of their reinforcement, and it may be understandable that for men there was no correlation between the FFI and the effect of a CF member on the marital relationship. It could be, as suggested by James & McIntrye (1983), that mother/child dyads with somewhat distant fathers may be within the scope of optimally functioning families.

That there may be an increased divorce rate or marital instability in CF families is neither supported nor disconfirmed by these data as all the respondents were married. The families of this study did not appear to have discordance or low marital integration as suggested by Pratt's study (1976). The high levels of communication and esteem found in this study may, in fact, be associated with marriage integration, stability, and satisfaction, tending to support the findings of Mikkelson, et al., (1978), and Begleiter (1976), that partners may be brought closer together with the presence of a CF family member. The marital dyad in CF families may tend to be stable because spouses know their roles, are open to new information, are well-organized and closely knit.

Siblings. Where there were other children in the family besides the CF member, the majority of men and women perceived the effect of the presence of the CF member on the lives of their other children to be generally positive. There was no correlation, however, between this positive perception and the Family Functioning Index. This positive perception lends support to the positive perceptions of siblings found by Taylor (1980), where siblings participated in caregiving. Had the

siblings been asked, the information may have been different than that obtained from the parents.

Outside Family Boundaries

Optimal functioning requires that families have boundaries which are relatively open, enabling the families to link with outside networks. In this study, family functioning was correlated with extended family social support for men.

Extended Family. Findings from the literature, previously reviewed, indicate that optimally functioning families have kinship support and are linked to a network outside their boundaries. Researchers studying CF families have not found that the extended family plays any supportive role. In this study, there was no correlation between extended family support and the FFI for women, although there was significant correlation between the two for men. It may be that women, as primary caregivers, do not think that the physical support offered by the extended family has an impact on the day-to-day functioning of the family. Alternatively, if external boundaries are somewhat closed, women may be reluctant to accept help from extended family members. Most men in this study were the major wage earners, worked outside the home and were, therefore, likely to be removed from much of the direct caregiving. Hence, they may perceive and assume there is care and support in terms of interest and concern on the part of extended family members. Such concern could then be viewed by men as affecting family functioning.

Respondents did not list any extended family members as residents

in their home, or as sources of help in providing CF care. The families in this study were nuclear families and respondents indicated that only parents and siblings of CF members provided care. In addition, sixteen percent of the sample had emigrated from abroad, thus reducing the opportunity to receive help from the extended family.

The extended family is apparently not as significant a support group for these CF families as might have been expected and it cannot be assumed that CF families will turn to kin for support. Although no additional data were collected from the respondents as to who did constitute such a support network for them besides extended family members, it may well be that other growth or support groups such as parents of other CF families, neighbours, or friends comprise such a support system, as indicated by Croog, et al., (1972).

Health Care Delivery System. Despite all the contact with and support provided by the health care system, no correlation was found between health care system variables and family functioning. Even though CF families on either end of the family functioning continuum had all the health care facilities at their disposal, some mediating elements, such as quality and quantity of personal or family resources, apparently existed between family functioning and use of the health care system. No matter how good the services are, the responsibility of carrying out treatment lies mainly in the hands of the primary caregiver who may reach out to other health care services when necessary. Consideration by members of the health care system must be given to the total family picture with all its ongoing events, to the family's ability and energy to take in and use available information,

as well as to the fact that some families may consider the importance of some resources and support more than others.

Sometimes openness to the health care delivery system involves little choice, since ongoing treatment is necessary for CF members to survive. For example, for some, hospitalization may occur only from time to time, while for others, it may increase with the severity of the disease and the family may then have more frequent contact with the health care system. As much of the treatment occurs at home, however, family boundaries are firm, opening only sufficiently to understand treatment strategies. These strategies may or may not then be carried out fully at home depending upon personal and family resources. Hence, contact with the health care delivery system, although important and necessary, bears no relation to the quality of family functioning.

Families are the milieu in which most of the care for the CF member is given and the caregivers should ideally be considered as health care team members although this does not always happen. CF family mothers in particular are responsible for many facets of care such as nutrition, medications, physiotherapy, equipment and emotional support which may be carried out in conjunction with household tasks and perhaps a job outside the home. Nutrition is learned, organized, and implemented through frequent adjustments of medication for weight gain, changes in tastes and levels of cooperation of the CF member. Chest physiotherapy may occur several times a day, perhaps involving use of medication in Nebulizers, followed by physical thumping to clear the chest. Finely tuned to the slightest change in the CF member, these primary caregivers are on constant duty, often teaching others

about the course of the disease and how to give care.

The nature of the contact and awareness of the r of use of health care services may be useful in understandin rface of the family and the health care system. For example, n used the services of the nurse and dietician more often than men perhaps because women provide most direct care to the CF family member. Men may have, more often than women, used the services of such disciplines as the pharmacist by picking up new or refilled prescriptions, enroute to and from the work place, thus providing indirect care to the CF member. The importance of the father's role in the CF family is becoming more visible and father[illegible]ear to be more involved than previously credited. Their s[illegible]nd involvement are reflected in the sharing of care, the supporti[illegible] the wife a[illegible] other family members, their economic role and the contact they have with other systems involved in ongoing care. In this study, men had contact with the same health care personnel as the women, a finding which was contrary to that of McKeever (1981).

The family is one system in a constellation of many. The CF family is in contact with many other systems, and, with their relatively closed boundaries, it would seem important for health care delivery personnel to consider this characteristic [illegible]not bombard them with information. Involving the family in assessing family strengths and resources as well as family needs can reduce ambiguity and a sense of helplessness, feelings which were expressed by some men and women in this study. The importance of awareness and understanding on the part of health care personnel as to why some families are not interested in

certain services and why some tend to depend heavily on others. The CF families may find phased delivery and reinforcement of information helpful as well as involvement in the determination of their needs and in the planning of more integrated care.

Because fathers and siblings are involved to some degree with caregiving, availability of services, such as CF Clinic appointments, at times when all members could attend periodically for consultation, assessment, or general involvement would be an asset to family and health care personnel. For example, evening and/or Saturday consultation times would enable more family members to attend without missing school or work, and would ease travelling and babysitting problems for some families from out of town.

Assessment of family strengths and weaknesses and degree of family functioning is not only useful for health care personnel in planning with CF families, but not difficult to do. Besides those instruments used in this study, other instruments and check lists exist such as Family Inventory of Life Events (FILE), Coping Health Inventory for Parents (CHIP), and Home Monitoring programs (Warwick, 1978) which includes the use of diaries, assessments of family functioning, and recording measures on children.

It may be that a family faced with hospitaliation of their CF member may have some predictable reactions. Hospitalization may relieve the family from a time-consuming routine of caregiving which may have reached a point of requiring more than the home environment could provide. On the other hand, hospitalization may result in a sense of failure on the part of the caregiver. Because of the emphasis

on daily ongoing home care, and because these families are highly structured, closely knit, organized, role-oriented and somewhat closed to outside systems, there may be a reluctance to give up roles and control to another system, even temporarily.

Comments from some respondents reflected hope that a CF family member would not get sick enough to have to be hospitalized and expressed concern that there be more communication between staff members and the family when a CF member was hospitalized. Because CF families are fairly structured, there may be some difficulty on the part of the family in being fluid about role change as in giving up or temporarily sharing caregiving with outsiders. This may result in the family's reluctance to readily open their boundaries to the hospital system.

Members of this sample of families expressed their desire to be more informed in language that was understandable and meaningful to them and to know what was happening and why. If families are to function optimally, it is important for mothers, who are more likely to be at the hospital or special clinic with the CF member, to have an understanding of appropriate medical aspects of this chronic illness.

Hospitalization of a CF member requires adaptation by all family members, particularly the mother who must give up part or all of her role as caregiver. Adaptation to the number of times in hospital may be more difficult and include different stresses than a long period of hospitalization. It may be that the stress for CF families is the process and frequency of hospitalization and not the actual number of days in hospital, so that hospitalization not be associated with the

level of family functioning.

It is difficult to generalize about the impact of the health care delivery system (HCDS) on the family process. The lack of correlation between the HCDS and the FFI may have to do with mediating variables such as diverse personal resources in the families, severity of the disease, and the varying amounts of care required by the CF individuals at different stages of the disease and the life cycle.

Knowledge about family organization could be useful to health care professionals who work with CF families. Family resources are basic to the quality of care that the CF child will receive. Yet if family boundaries are closed, health care personnel will have little knowledge of such resources. As one member of the sample said, "Until staff at the clinic know the family's financial and physical situations, they shouldn't pressure the parent." The skill required of families is to let the health care team know about their resources. The skill required of health care personnel is to allow families to use the information and skill they offer in the manner most appropriate to their family.

In view of some of the characteristics of these relatively optimally functioning CF families, an appropriate approach would be to meet the family with acknowledgement, understanding and appreciation of the importance of their ongoing role in the main care of their CF member. It would be beneficial for all involved to affirm, support and guide the family's caregiving role, to provide the time to hear and share the family's anxieties and fears associated with sharing or temporarily giving up control of care, and to involve the family

members as decision-makers and team members wherever possible. In addition, more must be written for CF families and health care personnel to read on family strengths and the importance of CF families as members of the health care team.

School. As CF children may spend much of their day in school, understanding of the nature and treatment of the disease on the part of the school personnel is important. This may be done by forming an aware, cohesive support system to promote greater understanding of the effect of emotional, cognitive and social aspects of CF on the child, family, teachers, caregivers and peers. There is also a need to emphasize the need for acceptance and a sense of normalcy for the CF member while encouraging academic achievements. Such a support group may be composed of CF families, pertinent representatives of the school (such as teacher, volunteers, nurse, etc.), and CF team (such as clinic coordinator, physiotherapist, etc.), and may be required to meet only as often as once or twice yearly during the school year.

Church. Although there was no correlation between moral religious expression and family functioning, respondents did indicate a level of importance on such expression. Men, for example, may have found it easier to seek emotional support from another man who was a minister. It is possible, too, that time constraints with care may have precluded any type of religious involvement, but not inhibited expression of moral-religious values. Such values as truth, honesty, fidelity, etc., may be communicated and shared daily in the family without necessarily having to be experienced within a set of verbalized beliefs or a formal religious framework.

Individual Resources

Potential opportunity for personal growth is important for individuals in optimally functioning families. Of the six individual resources which correlated with the family functioning index for women, only three of these were correlated for men, implying that individual resources tend to be more important for women, perhaps because they are the primary caregivers.

Physical and Mental Health. Promotion and acceptance of positive self-worth as well as the ability to provide for physical and emotional needs in the family are considered to be valuable characteristics of optimally functioning families. In this study, physical health and mental health were associated with family functioning for women only. Women in CF families who were primary caregivers most often carried out physiotherapy on the CF member and this required good physical health. In addition to these daily treatments, women managed households and also may have worked outside of the home. Understanding and interpreting all aspects of the CF care to other family members and giving and receiving emotional support within the family, a women in poor physical and mental health would certainly be less able to carry out her role. So it is not surprising that physical and mental health for women was positively associated with family functioning.

Men, who were the main financial supporters, had less direct involvement with family coordination and physical care of the CF member, and may not have required the rest and care women needed to give treatment. Hence, physical and mental health were not related to family functioning for men. Burton's (1975) findings that fathers

experienced health problems of a stress-related nature may be supported in part by the slightly lower levels of mental health reported by the men in this study.

Achievement Orientation. The higher the level of a family functioning, the lower the achievement orientation for both men and women. This finding may be interpreted as evidence of the focussing of personal energies on tasks within family. There may be subjugation of some individual goals which might have led to more optimal personal functioning. For example, negative responses were given to items like: "Getting ahead is very important in our family," "Family members are often compared with others as to how well they are doing at work or school", and "We believe in competition and may the best man win".

Many of the women who indicated that they had post-secondary education may have foregone previously anticipated career plans in order to concentrate their energy onto the increased care required within the family. Men, may also have forgone further outside career plans, and may have been reluctant to accept a promotion requiring a move away from CF facilities.

Active Recreation Orientation. There was an association between active recreation orientation and family functioning for women. Assessment of active recreation orientation was from positive responses to items like "We often go to movies, sports events, camping, etc.", and "Family members sometimes attend courses or take lessons for some hobby or interest (outside of school)". Women are the organizers of family activities and may see recreation as not only important for their own personal growth, but also for the well-being of other family

members. The emphasis on physiotherapy for the CF member requires a certain level of physical fitness on the part of the caregiver, and the treatment regime may include active recreation for the CF member or the whole family, perhaps in the form of swimming, gymnastics, hockey, cycling, etc. Men who are perhaps away from home for longer periods daily are less involved in planning and organizing activities and may be involved in caregiving to a lesser degree. It is probable that active orientation is not associated with levels of family functioning for men.

Education. Education was found to be related positively to family functioning for both men and women. In optimally functioning families, individuals must have the ability to help themselves and also to accept help (Otto, 1975). For men and women, education has the potential to enhance the ability to work in financially satisfying positions and to help seek information and resources and apply them for the benefit of all family members. For women in particular, education may enhance the ability to organize and plan treatment regimes to fit in along with routine household living. Education therefore would understandably be positively associated with family functioning.

Financial Well-Being. For both men and women, financial well-being was found to be positively asssociated with family functioning, not an unexpected result when respondents perceive that financial commitments could be met and they therefore could feel optimistic about their financial situation. Perceived adequacy of income has been consistently shown to be correlated with satisfaction with various aspects of one's life. Of interest here is the finding that while financial well-being was associated with family functioning,

actual income was not.

Women in CF families must be physically and mentally healthy and in a position to provide care to the CF member and other family members, so understandably, more individual resources for women were related to family functioning. The individual resources related to family functioning for men tended to be connected with their role as main wage earners. Men and women in these CF families appear to have down-played some of their personal goals.

Feedback

In optimally functioning families, the ability to be flexible and respond to new information from both inside and outside the family is considered important. For men and women in this study, organization, mastery and health, esteem and communication were found to be positively associated with family functioning while the number of CF members in the family was negatively associated with family functioning.

Organization. One of the ways of understanding the family's response to feedback is to look at current organization. In this study organization was correlated with the FFI for both men and women. Such a positive correlation provided a picture of highly structured families with emphasis on punctuality, planning of activities and good management.

Men and women placed slightly higher than average emphasis on organization by positively responding to items like "Being on time is very important in our family". Duties in the family were clearly defined and carried out on schedule. High levels of flexibility of

roles for some family members may not have been possible in light of the number of tasks required in caring for CF members. For example, some women may have foregone working outside the home, or involvement in other interests.

Mastery and Health. The family strength entitled Mastery and Health as measured in the Family Inventory of Resources for Management was positively associated with family functioning for both men and women. The parents in this study valued having some control over the direction of their lives as well as having good physical and mental health. Being involved with the daily ongoing care of a CF member requires some structure and agreed upon rules so that men and women may have a sense of control over and responsibility for the progress of the disease in the CF member. The level of control was demonstrated by the slightly above average scores for men and women on the Family Environment Scale where there were positive responses to items such as "There is a strong emphasis on following rules in our family", and "There are set ways of doing things at home".

Esteem and Communication. In optimally functioning families, communication is paramount as a clear, open, direct and successful exchange of information between family members, serving to enhance members' self-esteem. Esteem and communication assessed by items such as "We discuss our decisions with other family members before carrying them out", "The members of our family respect one another", and "In our family we understand what help we can expect from each other", were found to be positively correlated with family functioning. In a CF family schedule, it is important for all members to communicate with

each other in order to know what is happening to members or what changes are occurring in family subgroups such as the marriage relationship. Hence, CF family members who communicate and hold each other in high regard are more likely to function at a higher level because there is more emphasis on shared feelings and more discussion of decision-making and working to help each other.

Number of Children. Although adaptation is an ongoing process, no correlation was found between FFI and the number of years the families had been coping with CF. In fact, there was a negative correlation between the number of CF children in the family and the FFI. It appears that neither previous experience with CF nor length of experience enhance family functioning. Rather the addition of CF members reduces families' abilities to function well. It stands to reason that the addition to any family of members with a chronic illness would increase stress and be demanding of family resources.

CF Family Profile. In this study, the Family Environment Scale profile closely resembled that of the structure-oriented typology derived in the Moos & Moos (1976) study (see Appendix I). Profile scores of the CF families were slightly lower but parallel to the Moos profile scores in the relationship dimensions, while in the personal growth dimensions, all scores were below the Moos profile scores except for active-recreation. In the systems maintenance dimension of organization, the scores were above average for the CF families but considerably higher than the Moos profile scores. Both groups were above average with similar scores on the control subscale.

With energies focussed within the family to carry out required

care, it may be understandable that personal growth dimensions such as intellectual-cultural activities, independence and achievement-orientation may be curtailed. The families in this study showed a strong emphasis on structuring activities and on explicitness and clarity with regard to family rules and responsibilities. They were also highly organized and cohesive, committed to and supportive of the family and its members, and reflected below average conflict.

Conclusions

Resources associated with family functioning in Cystic Fibrosis families appear to be somewhat different than models in the literature would indicate (see Figure 10). For example, these relatively optimally functioning CF families were highly cohesive with highly permeable internal boundaries and somewhat selectively permeable external family boundaries. Also, internal relationships appeared to be characterized by enmeshment between caregivers and CF children, with a positive effect reported on the marital relationship. Whereas such family organization generally would be considered dysfunctional, in these CF families it was associated with high levels of family functioning.

Evidence of adaptative dimensions for CF families was the way they organized in terms of being clear about family rules and responsibilities and how energies within the family were directed at maintaining cooperation and integration of the family. The closeness and support in the family was enhanced by communication. The families were responsive to new information available from other sources, enabling them to cope.

OPTIMALLY FUNCTIONING FAMILIES	CF FAMILY FUNCTIONING
Boundaries	
- to outside: open - on inside: clear and open	- to outside: drawn, selectively permeable - inside: blurred, enmesh
- Bonding - appreciation mutual respect - cohesion intra family cooperation unity, connectedness	- high cohesion - low conflict
- open to new information. - marital coalition	- mother/child enmeshment - marital relationship important
- parental solidarity - clarity of family rules	- marital stability - shared care of children
- linking to the outside	- reduced time for outside networks
- contact with networks	- achievement orientation low for men and women
Feedback	
- communication - child rearing skills - flexibility of roles	- somewhat traditional with structured role clarity and division - highly organized - communication important - high level of control
Individual	
- personal growth - spiritual growth - self-help ability	- personal growth de-emphasized - physical and mental health important - moral-religious expression emphasized

Figure 10: Characteristics of Optimally Functioning Families Described in the Literature Compared with those of CF Families in the Study

Individual resources were more likely to be associated with family functioning for women who appeared to be the main coordinators of care and organizers of family life. In order to promote optimal family functioning, organization of families with a chronically ill member may require the subjugation of some individual goals, such as ordinarily might lead to optimal personal functioning. The amount of time and energy required to keep CF families running smoothly may have required that, despite the distinctly different male and female role-functions, both parents de-emphasized career and personal growth goals, which was evident in the low achievement orientation of both men and women. As well as being highly structured with clear division of roles and high value placed on these roles, these families were also nuclear families in which both parents were present and in which the majority of women remained in the home. This is not too different from families without CF members where traditional roles are followed with mother as caregiver and father as main wage-earner. Men were in contact with the health care system and perceived themselves to be more involved in sharing caregiving than previously credited. Men's roles in these CF families are quite different from those of their wives and their resources were apparently used quite differently.

Findings from the study are that the resources associated with family functioning in these relatively well-functioning CF families are somewhat different than models of optimally functioning families described in the literature indicate. Clearly, a single model is not adequate to explain optimal functioning in all types of families.

There have been more studies conducted on the physical aspects of

CF. Generally, of the few psychosocial-related studies, most have dwelt on the negative aspects which families must face. In this study, families functioned relatively well but they also reflected more concerns regarding emotional health than physical health. The admission of having feelings of anxiety and helplessness, of having to deal with depression in family members, of wanting more direct and honest information and communication from health care personnel, are all areas indicating a need on the part of the health care system for more awareness and knowledge of family functioning and of the numerous characteristics families assume in order to cope and to be "well-functioning". Health care personnel can enhance their present role for CF families by seeing a CF member in the context of the family unit, by acknowledging existing family strengths and by affirming the outstanding contributions these families make as integral members of the health team in delivering physical and emotional health care to their CF members. Health care personnel, when working along with CF families toward realistic goals, must also consider at which stage of the life cycle families may be and what other pertinent life events may also be occurring.

Implications for Future Research

There is a need for more research on the CF family unit particularly in the psychosocial area. Some topics for exploration are suggested here:

- Longitudinal studies of CF family functioning. What is the

impact on families at different stages of the family life cycle of having an offpsring diagnosed with CF?

- What are the important resources and supports for CF families at different stages of the disease as perceived by CF families and their subsystems?

- What do CF families perceive to be their family strengths at different stages in the family life cycle and at the different stages of the disease?

- What is the effect on the status of CF members' health on various levels on family functioning?

- What role does spiritual faith play as a family strength at different stages of the family life cycle and at different stages of the disease?

- Who comprises the psychosocial kinship group for CF families? Which groups are perceived to be most pertinent? Why, by whom, and in what way are they important?

- What impact does marriage of a CF member have on families of origin of both marriage partners. (As the life span slowly increases for some CF individuals, careers, marriage and child bearing are gradually emerging new territory. The changes for

parents of CF individuals as they ease out of caregiving roles to become in-laws and grandparents in an extended family support system have yet to be explored).

- What impact does a mother foregoing a career have on the CF family? On the mother? At different stages of the family life cycle?

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APPENDIX A:

Letter of Permission from CF Chapter President

Canadian
Cystic Fibrosis
Foundation
Fondation
Canadienne de la
Fibrose Kystique

212, 11803 - 125 Street
Edmonton, Alberta
May 30, 1981

Barbara Wheatley, R.N. B. Sc.
M. Sc. Candidate
Division of Family Studies
801 General Services Building
Edmonton, Alberta

Dear Mrs. Wheatley,

Thank you for your letter of May 26th outlining your study of Family Functioning Aspects of Cystic Fibrosis.

This was discussed at our regular May meeting and the Chapter gives approval for approaching families concerning C.F. with the following provisios:

1. privacy of patients and/or parents be respected; and,

2. a copy of final research paper be forwarded to the C.F. office so that it would be available to our membership.

We are looking forward to working with you and to the finalization of your study.

Yours very truly,

D. V. Rudkowski
Chapter President

DVR/dcr

APPENDIX B:

Letters of Endorsement and Invitation to Participate in the Study and Research Consent Form

212, 11803 - 125th Street
Edmonton, Alberta
T5L 0S1
(Telephone: 454-0568)

Dear

Members of the CF Chapter have always been interested and actively involved in doing all they could to increase the body of knowledge about CF. Much of this information so far has been about the physical aspects of the disease. Only in recent years has any work been started to find out about the effects of CF on other areas of life, particularily family life.

The Chapter Executive is pleased to announce that research in this area will be started this September in the Family Studies Department of The University of Alberta by Dr. Norah Keating, Professor and Research Consultant, and Barbara Wheatley, R.N., Family Studies M.Sc. Candidate, and a former CF Clinic Coordinator. We are enthusiastic and encouraged that Edmonton and Area are beginning such research here in CF. The project has been funded by the Medical Services Incorporated Foundation of Alberta.

This letter is an invitation to you to take part in this project. In keeping with the Chapter's policy of Confidentiality, this letter has been sent to you privately. We encourage you to read the enclosed letter from Dr. Keating and Mrs. Wheatley, and to reply soon. All replies will be returned to our own office and only "yes" replies will be forwarded to the investigators.

Yours very truly,

D. V. Rudkowski
Chapter President

family studies
FACULTY OF HOME ECONOMICS
THE UNIVERSITY OF ALBERTA • EDMONTON, CANADA • T6G 2M8

September 1st, 1981

We are beginning a study of families with (a) CF member(s) living in the northern half of Alberta. We wish to include all family types: two parent or single parent, divorced, remarrieds or common-law, CF members at home or living out, etc.

The study has been designed to gather information on how families with CF members function in day-to-day life with a view to looking at characteristics that may help or hinder such families. It is anticipated that such information may be of great value in better understanding the situation of people like yourselves. We would like to talk to both members of the couple, where applicable, and enclose a consent form for each.

We are writing to ask your cooperation in gathering this information. We appreciate that it will take your valuable time to contribute to this important research, but also feel that you have a great deal of valuable first-hand information to offer. We need as many families as possible to make our study valid. Please read, sign, and return the enclosed form in the enclosed self-addressed envelope.

Your assistance is greatly appreciated and we will look forward to talking with you soon. Please call for any additional information you may desire.

Sincerely,

N. Keating

Norah Keating, Ph.D.
(Telephone: 432-4191)

B Wheatley

Barbara Wheatley, R.N., B.Sc.
(Telephone: 432-5141 days; 459-3894 - evenings)

Enclosures

RESEARCH CONSENT FORM

FAMILY FUNCTIONING WITH CYSTIC FIBROSIS

This is to certify that I _____ have given Consent to participate in a research project being conducted by Dr. Norah Keating, Ph.D., and Mrs. Barbara Wheatley, Registered Nurse. I understand that I will fill out four questionnaires which will provide information on family functioning with a Cystic Fibrosis member.

I also understand that:

1. The information will be given in my own home or other convenient place at my convenience through prior telephone arrangements.
2. The appointment will last about 45 minutes to one hour.
3. I am free to withdraw from the project at any time.
4. All reports on the project will be compiled in such a way that privacy of all individual families will be guaranteed.
5. The Confidential information gathered will not be released by the investigator to anyone outside the research project.
6. A summary of the findings of the study will be sent to all participants with the opportunity to contact the investigator with questions or for further discussion.

Name: (Please Print) _____

Signature: _____

Date: _____

Telephone number for interview: _____

I do not wish to take part in the study: ____

Name: (Please Print) _____

Date: _____

I have participated in other research projects. Yes ___ No ____

If yes, what was the project? _____

_____ _____

_____

APPENDIX C:

Family Functioning Index (FFI)

FAMILY FUNCTIONING INDEX

The following is a list of questions to be answered by you and your partner [where applicable]. They will help us to gain a better understanding of family life. Please do not discuss the questions until after you have completed the questionnaire and returned it to the interviewer. Your answers will be CONFIDENTIAL. DO NOT SIGN YOUR NAME ANYWHERE ON THE FORMS.

1. Date: _____

2. What sorts of things do you do as a family?

   (a) In the evenings -

   (b) On the weekends -

   (c) On vacations -

PUT A CHECK IN THE BOX CORRESPONDING TO YOUR ANSWER

3. How do you think the children get along together compared with other families? (Disregard if only one child.)

   ☐ Better ☐ Same ☐ Worse

4. Do the children find it easy to talk to you about their problems?

   ☐ Yes ☐ Sometimes ☐ No

5. Do the children find it easy to talk to your partner about their problems?

   ☐ Yes ☐ Sometimes ☐ No

6. Do you find your partner an easy person to talk to when something is troubling you?

   ☐ Yes ☐ Sometimes ☐ No

7. Is your partner able to spend a lot of time with the children in the evening?

   ☐ Yes ☐ Sometimes ☐ No

8. Is your partner able to spend a lot of time with the children on the weekend?

   ☐ Yes ☐ Sometimes ☐ No

9. Are you able to spend a lot of time with the children in the evening?

☐ Yes ☐ Sometimes ☐ No

10. Are you able to spend a lot of time with the children on the weekend?

☐ Yes ☐ Sometimes ☐ No

11. Would you say, all in all, that your family is happier than most others you know, about the same, or less happy?

☐ Happier ☐ Same ☐ Less happy

12. What would you say was the most important problem you as a family had to deal with this year?

	Yes	No
a) Was a solution arrived at?	☐	☐
b) Did you discuss the problem with your partner?	☐	☐
c) Was everyone satisfied with the solution?	☐	☐

3.

13. In every family someone has to decide such things as where the family will live and so on. Many couples talk about such things with the family first, but the final decision often has to be made by one partner or the other. If these situations you have not decided on recently, how would they be decided on should they occur?

1 = He always
2 = He more than she
3 = He + She exactly the same
4 = She more than he
5 = She always

[Write in the number corresponding to your choice]

a) Who usually makes the final decision about what kind of car to get? ____

b) ... about whether or not to buy life insurance? ____

c) ... about what house or apartment to take? ____

d) ... about what job your partner should take? ____

e) ... about whether or not you should go to work or quit work? ____ .

14. Thinking of marriage in general, which one of these five things would you say is the most valuable part of your marriage?

1 = the chance to have children
2 = the standard of living - the kind of house, clothes, car and so forth
3 = His/Her understanding of his/her problems + feelings
4 = His/Her expression of love and affection for him/her.
5 = Companionship and doing things together with him/her.

[Write in the number corresponding to your choice, using each number only once.]

a) The most valuable part of marriage ____

b) The next most valuable ____

c) Third most valuable ____

d) Fourth most valuable ____

e) Fifth most valuable ____

4.

15. Of course, most couples differ sometimes over things. When you and your partner differ about something, do you usually give in and do it their way, or does your partner usually come around to your point of view?

☐ partner's way ☐ 50/50 ☐ own way

16. Would you say disagreements in your household come up more often, about the same, or less often than in other families you know?

☐ More often ☐ Same ☐ Less often

17. Would you say that compared to most families you know, you feel less close to each other, about the same, or closer than other families do?

☐ Less close ☐ Same ☐ Closer

18. The following are some feelings you might have about certain aspects of marriage.

1 = Pretty disappointed. I'm really missing out on that.
2 = It would be nice to have more.
3 = It's all right, I guess - I can't complain.
4 = Quite satisfied - I'm lucky the way it is.
5 = Enthusiastic - it couldn't be better.

[Write in the number corresponding to your choice.]

a) How do you feel about your standard of living, the kind of house, clothes, car, and so forth? ____

b) How do you feel about the understanding you get of your problems and feelings? ____

c) How do you feel about the love and affection you receive? ____

d) How do you feel about the companionship of doing things together? ____

5

19. When your partner comes home from work, how often do they talk about things that happened there?

☐ Very often ☐ Sometimes ☐ Never

end of Index

20. How do you perceive the effect of your CF member(s) on your relationship with your partner at this time? [Check one]

☐ Highly positive ☐ Somewhat positive ☐ Somewhat negative ☐ Highly negative

21. How has the presence of a CF member in your household affected the lives of your other children? [Check one.]

☐ Highly positive ☐ Somewhat positive ☐ Somewhat negative ☐ Highly negative

APPENDIX D:

Family Environment Scale (FES)

A SOCIAL CLIMATE SCALE

FAMILY ENVIRONMENT SCALE

FORM R

RUDOLF H. MOOS

INSTRUCTIONS

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheets. If you think the statement is *True* or mostly *True* of your family, make an X in the box labeled T (true). If you think the statement is *False* or mostly *False* of your family, make an X in the box labeled F (false).

You may feel that some of the statements are true for some family members and false for others. Mark T if the statement is *true* for most members. Mark F if the statement is *false* for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

Remember, we would like to know what your family seems like to *you*. So *do not* try to figure out how other members see your family, but *do* give us your general impression of your family for each statement.

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577 College Ave., Palo Alto, California 94306

1. Family members really help and support one another.
2. Family members often keep their feelings to themselves.
3. We fight a lot in our family.
4. We don't do things on our own very often in our family.
5. We feel it is important to be the best at whatever you do.
6. We often talk about political and social problems.
7. We spend most weekends and evenings at home.
8. Family members attend church, synagogue, or Sunday School fairly often.
9. Activities in our family are pretty carefully planned.
10. Family members are rarely ordered around.
11. We often seem to be killing time at home.
12. We say anything we want to around home.
13. Family members rarely become openly angry.
14. In our family, we are strongly encouraged to be independent.
15. Getting ahead in life is very important in our family.
16. We rarely go to lectures, plays or concerts.
17. Friends often come over for dinner or to visit.
18. We don't say prayers in our family.
19. We are generally very neat and orderly.
20. There are very few rules to follow in our family.
21. We put a lot of energy into what we do at home.
22. It's hard to "blow off steam" at home without upsetting somebody.
23. Family members sometimes get so angry they throw things.
24. We think things out for ourselves in our family.
25. How much money a person makes is not very important to us.
26. Learning about new and different things is very important in our family.
27. Noboby in our family is active in sports, Little League, bowling, etc.
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.
29. It's often hard to find things when you need them in our household.
30. There is one family member who makes most of the decisions.
31. There is a feeling of togetherness in our family.
32. We tell each other about our personal problems.
33. Family members hardly ever lose their tempers.
34. We come and go as we want to in our family.
35. We believe in competition and "may the best man win."
36. We are not that interested in cultural activities.
37. We often go to movies, sports events, camping, etc.
38. We don't believe in heaven or hell.
39. Being on time is very important in our family.
40. There are set ways of doing things at home.
41. We rarely volunteer when something has to be done at home.
42. If we feel like doing something on the spur of the moment we often just pick up and go.
43. Family members often criticize each other.
44. There is very little privacy in our family.
45. We always strive to do things just a little better the next time.
46. We rarely have intellectual discussions.
47. Everyone in our family has a hobby or two.
48. Family members have strict ideas about what is right and wrong.
49. People change their minds often in our family.
50. There is a strong emphasis on following rules in our family.
51. Family members really back each other up.
52. Someone usually gets upset if you complain in our family.
53. Family members sometimes hit each other.

54. Family members almost always rely on themselves when a problem comes up.
55. Family members rarely worry about job promotions, school grades, etc.
56. Someone in our family plays a musical instrument.
57. Family members are not very involved in recreational activities outside work or school.
58. We believe there are some things you just have to take on faith.
59. Family members make sure their rooms are neat.
60. Everyone has an equal say in family decisions.
61. There is very little group spirit in our family.
62. Money and paying bills is openly talked about in our family.
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
64. Family members strongly encourage each other to stand up for their rights.
65. In our family, we don't try that hard to succeed.
66. Family members often go to the library.
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).
68. In our family each person has different ideas about what is right and wrong.
69. Each person's duties are clearly defined in our family.
70. We can do whatever we want to in our family.
71. We really get along well with each other.
72. We are usually careful about what we say to each other.
73. Family members often try to one-up or out-do each other.
74. It's hard to be by yourself without hurting someone's feelings in our household.
75. "Work before play" is the rule in our family.
76. Watching T.V. is more important than reading in our family.
77. Family members go out a lot.
78. The Bible is a very important book in our home.
79. Money is not handled very carefully in our family.
80. Rules are pretty inflexible in our household.
81. There is plenty of time and attention for everyone in our family.
82. There are a lot of spontaneous discussions in our family.
83. In our family, we believe you don't ever get anywhere by raising your voice.
84. We are not really encouraged to speak up for ourselves in our family.
85. Family members are often compared with others as to how well they are doing at work or school.
86. Family members really like music, art and literature.
87. Our main form of entertainment is watching T.V. or listening to the radio.
88. Family members believe that if you sin you will be punished.
89. Dishes are usually done immediately after eating.
90. You can't get away with much in our family.

APPENDIX E:

Family Inventory of Resources for Management (FIRM)

University of Minnesota
Family Social Science
290 McNeal Hall
St. Paul, Minnesota

Medical Education and Research
Association of
Gillette Children's Hospital

Family Health Program
FORM B
1981

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Hamilton I. McCubbin Joan K. Comeau Jo A. Harkins

PURPOSE

FIRM — Family Inventory of Resources for Management was developed to record what social, psychological, community and financial resources families believe they have available to them in the management of family life.

DIRECTIONS

To complete this inventory you are asked to read the list of **"Family Statements"** one at a time. In each statement, "family" means your immediate family (mother and/or father and children).

Then ask yourself: "HOW WELL DOES THE STATEMENT DESCRIBE OUR FAMILY SITUATION?"

Then make your decision by circling one of the following:

(0) = *Not At All* — This statement does not describe our family situation. This does not happen in our family.

(1) = *Minimally* — This statement describes our family situation only slightly. Our family may be like this once in a while.

(2) = *Moderately* — This statement describes our family situation fairly well. Our family is like this some of the time.

(3) = *Very Well* — This statement describes our family very accurately. Our family is like this most of the time.

PLEASE BEGIN — Please read and record your decision for EACH and EVERY statement below.

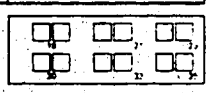
COMPUTER CODES: IID □□□□ GID □□□ FAMID □□□□$_{11}$

Purchased from the authors
University of Minnesota
Family Social Science
290 McNeal Hall
St. Paul, Minnesota.

	FAMILY STATEMENTS	Describes Our Family: Not at all	Minimally	Moderately	Very Well	For Computer Use: SFS	RS	SD
1	We have money coming in from our investments (such as rental property, stocks, bonds, etc.)	0	1	2	3	☐	○	
2	Being physically tired much of the time is a problem in our family	0	1	2	3	○	☐	
3	We have to nag each other to get things done	0	1	2	3		☐	○
4	We do not plan too far ahead because many things turn out to be a matter of good or bad luck anyway	0	1	2	3	○	☐	
5	Our family is as well adjusted as any family in this world can be	0	1	2	3		○	☐
6	Having only one person in the family earning money is (or would be) a problem in our family	0	1	2	3	○	☐	
7	It seems that members of our family take each other for granted	0	1	2	3		☐	○
8	Sometimes we feel we don't have enough control over the direction our lives are taking	0	1	2	3	○	☐	
9	Certain members of our family do all the giving, while others do all the taking	0	1	2	3		☐	○
10	We depend almost entirely upon financial support from welfare or other public assistance programs	0	1	2	3	☐	○	
11	We seem to put off making decisions	0	1	2	3	○	☐	
12	Family members understand each other completely	0	1	2	3		○	☐
13	Our family is under a lot of emotional stress	0	1	2	3		☐	○
14	Many things seem to interfere with family members being able to share concerns	0	1	2	3		☐	○
15	Most of the money decisions are made by only one person in our family	0	1	2	3	○	☐	
16	There are times when family members do things that make other members unhappy	0	1	2	3		○	☐
17	It seems that we have more illness (colds, flu, etc.) in our family than other people do	0	1	2	3		☐	○
18	In our family some members have many responsibilities while others don't have enough	0	1	2	3	○	☐	
19	No one could be happier than our family when we are together	0	1	2	3		○	☐
20	It is upsetting to our family when things don't work out as planned	0	1	2	3		☐	○
21	We depend almost entirely on income from alimony and or child support	0	1	2	3	☐	○	
22	Being sad or "down" is a problem in our family	0	1	2	3	○	☐	
23	It is hard to get family members to cooperate with each other	0	1	2	3		☐	○
24	If our family has any faults, we are not aware of them	0	1	2	3		○	☐
25	We depend almost entirely on social security retirement income	0	1	2	3	☐		○
26	Many times we feel we have little influence over the things that happen to us	0	1	2	3	○	☐	
27	We have the same problems over and over—we don't seem to learn from past mistakes.	0	1	2	3		☐	○
28	One or more working members of our family are presently unemployed	0	1	2	3	☐	○	
29	There are things at home we need to do that we don't seem to get done	0	1	2	3		☐	○
30	We feel our family is a perfect success	0	1	2	3	○		☐
31	We own land or property besides our place of residence	0	1	2	3	☐	○	
32	We seem to be so involved with work and or school activities that we don't spend enough time together as a family	0	1	2	3		☐	○
33	We own (are buying) a home (single family, condominium, townhouse, etc.)	0	1	2	3	☐	○	
34	There are times when we do not feel a great deal of love and affection for each other	0	1	2	3		○	☐

SFS RS SD

	FAMILY STATEMENTS	Describes Our Family: Not at all	Minimally	Moderately	Very Well	For Computer Use FS	FWB	SS
36	If a close relative were having financial problems we feel we could afford to help them out	0	1	2	3		□	○
38	Friends seem to enjoy coming to our house for visits	0	1	2	3	□		○
37	We feel we have a good retirement income program	0	1	2	3	○	□	
38	When we make plans we are almost certain we can make them work	0	1	2	3	□		○
39	In our family we understand what help we can expect from each other	0	1	2	3	□	○	
40	We seem to have little or no problem paying our bills on time	0	1	2	3	○	□	
41	Our relatives seem to take from us, but give little in return	0	1	2	3		○	□
42	We would have no problem getting a loan at a bank if we wanted one	0	1	2	3	○	□	
43	We feel we have enough money on hand to cover small unexpected expenses (under $100)	0	1	2	3		□	○
44	When we face a problem, we look at the good and bad of each possible solution	0	1	2	3	□	○	
45	The member(s) who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.)	0	1	2	3	○	□	
46	No matter what happens to us, we try to look at the bright side of things	0	1	2	3	□	○	
47	We feel we are able to go out to eat occasionally without hurting our budget	0	1	2	3		□	○
48	We try to keep in touch with our relatives as much as possible	0	1	2	3		○	□
49	It seems that we need more life insurance than we have	0	1	2	3		□	○
50	In our family it is "okay" for members to show our positive feelings about each other	0	1	2	3	□	○	
51	We feel we are able to make financial contributions to a good cause (needy people, church, etc.)	0	1	2	3		□	○
52	We seem to be happier with our lives than many families we know	0	1	2	3	□	○	
53	It is "okay" for family members to express sadness by crying, even in front of others	0	1	2	3	□	○	
54	When we need something that can't be postponed, we have money in savings to cover it	0	1	2	3	○	□	
55	We discuss our decisions with other family members before carrying them out	0	1	2	3	□	○	
56	Our relative(s) are willing to listen to our problems	0	1	2	3		○	□
57	We worry about how we would cover a large unexpected bill (for home, auto repairs, etc. for about $100)	0	1	2	3	○	□	
58	We get great satisfaction when we can help one another in our family	0	1	2	3	□		○
59	In our family we feel it is important to save for the future	0	1	2	3		□	○
60	The working members of our family seem to be respected by their co-workers	0	1	2	3	□		○
61	We have written checks knowing there wasn't enough money in the account to cover it	0	1	2	3	○	□	
62	The members of our family respect one another	0	1	2	3	□	○	
63	We save our extra spending money for special things	0	1	2	3	○	□	
64	We feel confident that if our main breadwinner lost his/her job, (s)he could find another one	0	1	2	3	○	□	
65	Members of our family are encouraged to have their own interests and abilities	0	1	2	3	□		○
66	Our relatives do and say things to make us feel appreciated	0	1	2	3	○		□
67	The members of our family are known to be good citizens and neighbors	0	1	2	3	□	○	
68	We make an effort to help our relatives when we can	0	1	2	3	□	○	
69	We feel we are financially better off now than we were 5 years ago	0	1	2	3		□	○



FS FWB SS

PLEASE Check all 69 items to be sure you have circled a number for each one. THIS IS IMPORTANT

APPENDIX F:

General Information Questionnaire

GENERAL INFORMATION QUESTIONNAIRE

1. Female _____ Male _____

2. (a) Date of birth: _____

   (b) Country of birth: _____

   (c) With which ethnic group do you identify: _____

3. Present marital status:

   Widowed _____ for ___ years
   Single (never married) _____
   Married _____ for ___ years
   Separated _____ for ___ years
   Divorced _____ for ___ years
   Remarried _____ for ___ years
   Living together (unmarried) ___ for ___ years.

4. Children in the family:

(a)

		AGE	SEX	YOUR NATURAL CHILD? Yes?	No?	IF NO, EXPLAIN (See *)	LIVING WITH YOU? Yes?	No?	DECEASED (Date)	DIAGNOSED CF Yes	Mo	IF Yes Date of Diagnosis	Any other ongoing health problems? SPECIFY.	IS THE CF Slight/Mild/Moderate/Severe	Number of Days Hospitalized in the last 12 months? (of CF members)
First born -	1														
	2														
	3														
	4														
	5														
	6														
	7														
	8														
	9														

* (eg: adopted, spouse's child, foster, relative)

(b) Please list other people living in your household besides the above and yourself.

AGE	SEX	NATURE OF RELATIONSHIP	LENGTH OF RESIDENCE WITH YOU

(c) Who is the primary (main) care-giver of your CF member(s)? Check ONE.

Mother ___
Father ___
Brother ___
Sister ___
Other. (specify) _____

(d) Who else helps with the care of your CF member?

Mother ___
Father ___
Brother ___
Sister ___
Other (Specify) _____

(e) How cooperative is your CF member about their treatment? (Circle one)

Very cooperative			Uncooperative
1	2	3	4

(f) Do other family members in your home have any handicaps? Yes ___ No ___

If yes, which member(s) _____

What is the nature of the handicap(s)? _____

(g) Compared with other people your age, how would you rate your physical health? (Circle one)

Excellent			Poor
1	2	3	4

Compared with other people your age, how would you rate your mental health? (Circle one)

Excellent			Poor
1	2	3	4

5. What is the highest level of formal education you have attained?

CHECK ONE ONLY:
___ Up to 8 years
___ 9 to 12 years
___ Some university and/or other post-secondary (eg: courses at a technical school, community college, or business school)
___ Graduate degree
___ Completed other post-secondary training (diploma received)

6. Are you employed?
___ full-time
___ part-time
___ no
___ retired

7. What is your present job? _____

8. What is your individual yearly income before taxes?

_____ Under $5,000
_____ $ 6,000 - $10,000
_____ $11,000 - $15,000
_____ $16,000 - $20,000
_____ $21,000 - $25,000
_____ $26,000 - $30,000
_____ $31,000 and over

9. How many times have you moved in the last two (2) years? _____

10. How long have you lived in your present dwelling? _____

11. How many bedrooms are there in your home? _____

12. Do you own your own home? Yes___ No ___

13. How many people live in your home? _____

14. How many miles from Edmonton is your home?

___ live in Edmonton
___ up to 25 miles from Edmonton
___ 26-50 miles from Edmonton
___ 51-100 miles from Edmonton
___ 101-150 miles from Edmonton
___ 151-200 miles from Edmonton
___ over 200 miles from Edmonton

15. Does your CF member attend public school?

Yes ___ No ___

If Yes,
How many days of school were missed in the last year? ___

If No, explain: _____

How do you rate school cooperation regarding your child's CF?

Cooperative 1 2 3 4 Uncooperative

16. In the last 12 months, which of these people and/or services

	(A) Did you use? (Check off)	(B) was used the most? (List in order 1-2-3, etc.)	(C) was needed but not available? (Check off)	(D) gave main emotional support? (List in order 1-2-3, etc.
1. Minister				
2. Family Doctor				
3. School Teachers				
4. CF Clinic doctor				
5. Psychologist				
6. Nurse				
7. Family Counsellor				
8. Physiotherapist				
9. Social Worker				
10. Nutritionist (Dietitian)				
11. Pharmacist				
12. Inhalation Therapist				
13. Other (Specify)				
14. Genetic Counsellor				

17. What particular concerns do you have at this point in time about your CT member(s)?

18. We invite any further comments...

THANK YOU VERY MUCH FOR TAKING TIME TO ANSWER THESE QUESTIONS.

YOUR VALUABLE CONTRIBUTION IS GREATLY APPRECIATED!

APPENDIX G:

Variables

APPENDIX G

VARIABLES

1. Demographic

FFI-20 effect CF on marital relationship
FFI-21 effect CF on siblings

age
ethnic
number of live children
information on all children (child one, child two, child three, child four)
- age 1st child
- sex
- biological child
- not biological
- living at home
- deceased
- years deceased
- child 1 with CF
- how long CF
- other health problems
- if so - what
- severity of CF
- days hosp. with CF in last 12 months
- primary care giver
- other help with care
- CF's cooperation with treatment
- other handicaps in family
- physical health respondent
- mental health respondent
- education of respondent
- whether employed, part/full/non
- nature of occupation
- income bracket
- number of household moves last 2 years
- number of years in present residents
- number of bedrooms in home
- own the residence?
- number people living in residence
- number miles from Edmonton
- does CF attend school?
- number of days CF absent/school
- CF does not attend school
- school cooperation re CF
- participated in previous research

health care contacts (used, most used, main emotional support)
- minister used
  - minister most used
  - minister main emotional support
- family doctor used
  - family doctor most used
  - family doctor main emotional support
- school teacher used
  - school teacher most used
  - school teacher main emotional support
- CF clinic doctor used
  - CF clinic doctor most used
  - CF clinic doctor main emotional support
- psychologist used
  - psychologist most used
  - psychologist main emotional support
- nurse used
  - nurse most used
  - nurse main emotional support
- family counseller used
  - family counsellor most used
  - family counsellor main emotional support
- physiotherapist used
  - physiotherapist most used
  - physiotherapist main emotional support
- social worker used
  - social worker most used
  - social worker main emotional support
- dietician used
  - dietician most used
  - dietician main emotional support
- pharmacist used
  - pharmacist most used
  - pharmacist main emotional support
- inhalation therapist used
  - inhalation therapist most used
  - inhalation therapist main emotional support
- genetetic counsellor used
  - genetetic counsellor most used
  - genetetic counsellor main emotional support

2. Family Functioning Index Scores

3. FES Variables

Cohesion
Expressiveness
Conflict
Independence
Achievement orientation
Intellectual-cultural orientation

Active-recreational orientation
Moral-religious emphasis
Organization
Control

4. FIRM Variables

Family Strengths I: Esteem & Communication
Family Strengths II: Mastery & Health
Extended Family Social Support
Financial Well-being
Sources of Financial Support
Social Desirability

APPENDIX H:

Respondents' Comments and Concerns

RESPONDENTS' COMMENTS AND CONCERNS

HEALTH CARE AND OTHER SYSTEMS

- Pleased with care received at the CF Clinic.
- Want more direct information from doctors regarding CF members' progress.
- Want doctors to be more open about CF member's condition and to relay that information in understandable language so that parent does not leave more worried than before.
- More doctors in this area need to be better informed about CF.
- Blue Cross should fully cover CF members over the age of 18.
- Government should take over full medical expenses for CF.
- Need for a Children's Hospital in Edmonton.
- That the traumatic experience of hospitalization will not be necessary when CF member is hospitalized.
- Until staff at Clinic really know the family's financial and physical situation, they should hold off pressuring a parent.
- Wanted more contact with other CF parents.
- Hope that CF member does not get sick enough to go to hospital.
- Feel like an outsider at the busy Clinic.
- Found great strength and support from other CF families.
- Concerned about adjustment in starting school and how other children will react to CF.
- Worry about CF member's failure in school.
- How the public reacts to CF - public is poorly informed.

PHYSICAL HEALTH

- Life expectancy.
- Getting CF members to take pills.

- Weight gain concern, day-to-day health.
- Diet, coping with junk food, number of pills for snacks, etc.
- CF's physical condition later, how long will it remain good; when will it become severe?

EMOTIONAL HEALTH

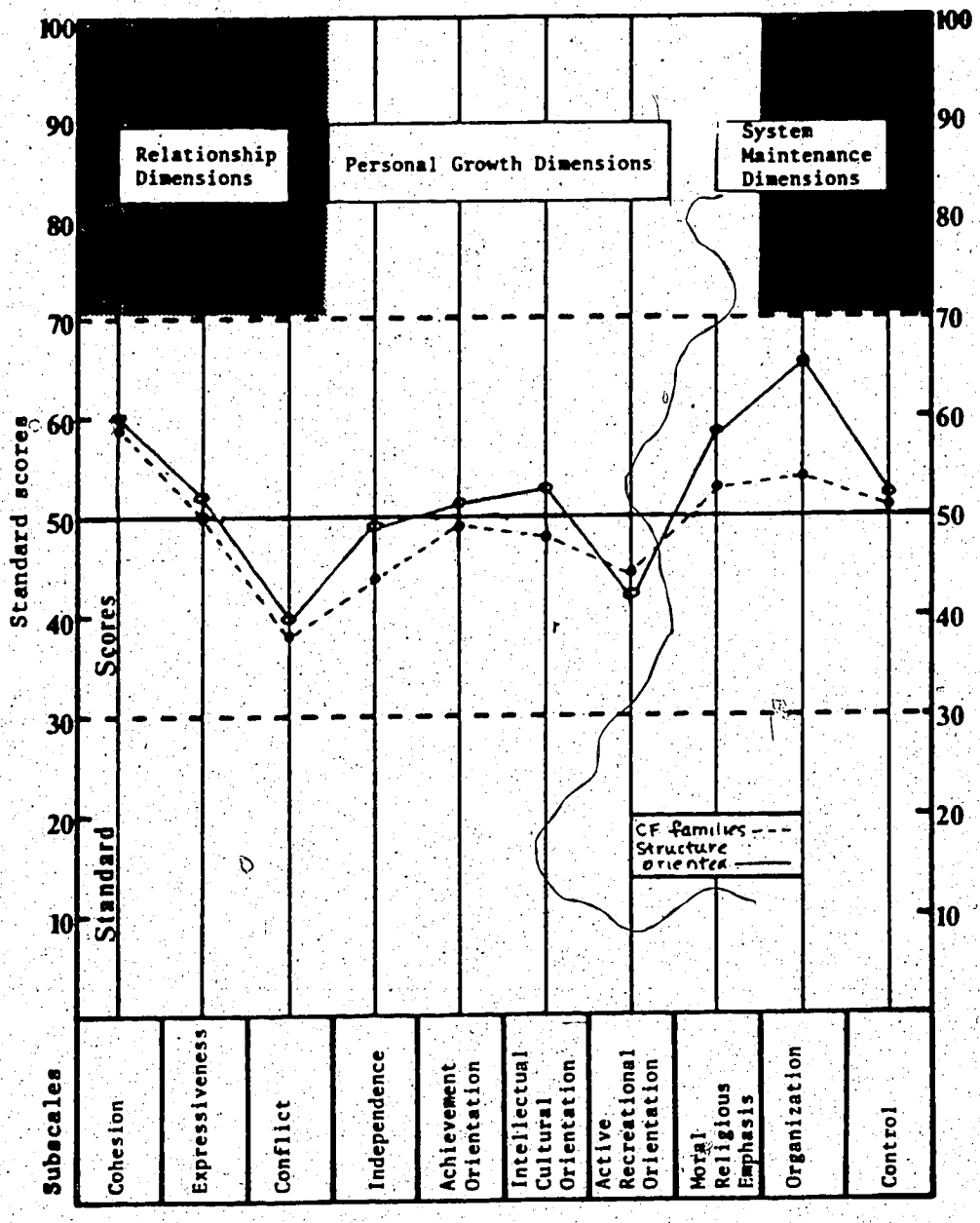
- Worry about CF member coping when they leave home.
- Concern about future health and mental well-being.
- Worry about one CF member being affected more than the other CF member.
- Concern about whether the CF member has any anxiety about death, fear of raising the subject.
- Depression being hard to deal with in CF member.
- Feelings of helplessness.
- Having a CF has enabled better coping with stress through being strong for the CF member.
- Will CF member ever have own children? Will a CF son be able to father children?
- Concern that appropriate vocational guidance be given to enable CF member to pursue a suitable job.

RESEARCH

- What is the progress of current research? Desire for more research to help children lead longer and more natural lives.
- Looking for reassurance that research will go, further wanting longer lives for CF members.
- More studies on young adult CF members needed.
- Compare how families used to be before CF with how they are now with CF.

APPENDIX I:

Comparison of Structure-Oriented Typology (Moos & Moos, 1976) and CF Families


Relationship Dimensions
Personal Growth Dimensions
System Maintenance Dimensions
Standard scores
Standard Scores
100
90
80
70
60
50
40
30
20
10
CF families ---
Structure oriented ——
Subscales
Cohesion
Expressiveness
Conflict
Independence
Achievement Orientation
Intellectual Cultural Orientation
Active Recreational Orientation
Moral Religious Emphasis
Organization
Control

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APPENDIX J:

Letters of Permission to Include Reproductions of FIRM and FES in Appendix of Thesis

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Edmonton, Canada T6G 2M8

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TWIN CITIES

Family Social Science
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St. Paul, Minnesota 55108
(612) 373-1578

May 18, 1983.

Barbara Wheatley, B.Sc.
Department of Family Studies
801 General Services Building
University of Alberta
Edmonton, Alberta T6G 2M8
CANADA

Dear Ms. Wheatley:

In response to your letter of April 25th, I am pleased to give you permission to include FIRM: Family Inventory of Resources for Management, in the appendix of your master's thesis.

If I can be of any further assistance, please feel free to write or call.

Sincerely,

Hamilton I. McCubbin
Professor and Head

HIM:sr-j